DOCTOR OF PHILOSOPHY

LSRP: Defence styles, alexithymia, illness perceptions, and HRQOL in IBD. Systematic lit: Neurodegenerative diseases and third wave therapies

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Award date:
2018

Awarding institution:
Queen's University Belfast

Doctorate in Clinical Psychology (D.Clin.Psych)

School of Psychology

LSRP: Defence styles, alexithymia, illness perceptions, and HRQOL in IBD.

Systematic lit: Neurodegenerative diseases and third wave therapies.

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May 2018

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Acknowledgements

I would like to express my sincere gratitude to Dr Martin Dempster, Dr Noleen McCrory and Dr Emma Berry for their assistance and suggestions throughout the systematic literature review.

List of abbreviations

ACT	Acceptance and Commitment Therapy
AD	Alzheimer's disease
ALS	Amyotrophic Lateral Sclerosis
ALSSQOL-R	Amyotrophic Lateral Sclerosis -Specific Quality Of Life Scale Revised
BAI	Beck Anxiety Inventory
BDI	Beck Depression Inventory
CAMCOG	Cambridge Cognition Examination
COMET	Core Outcome Measures in Effectiveness Trials
CSDD	Cornell Scale for Depression in Dementia
DASS 21	Depression Anxiety Stress Scales -21
DBT	Dialectical Behaviour Therapy

DSM	Diagnostic and Statistical Manual of Mental Disorders
FFMQ	Five Facet Mindfulness Questionnaire
FMI	Freiburg Mindfulness Inventory
GSES	General Self-Efficacy Scale
HADS	Hospital Anxiety and Depression Scale
JPND	Joint Programme for Neurodegenerative Disease
MBAS	Mindfulness Based Alzheimer's Stimulation
MBCT	Mindfulness Based Cognitive Therapy
MBSR	Mindfulness-Based Stress Reduction
MMSE	Mini-Mental State Examination
NICE	National Institute for Health and Care Excellence

NINCDS-ARDA	National Institute of Neurological and Communicative Disorders and Stroke - Alzheimer's Disease and Related Disorders Association
PD	Parkinson’s disease
PDQ-39	Parkinson’s Disease Questionnaire-39
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta- Analyses
PSS-13	Perceived Stress Scale -13
QOL	Quality of Life
QOL-AD	Quality of Life Alzheimer’s Disease scale
RAIDS	Rating Anxiety in Dementia Scale
RCT	Randomised controlled trials
UPDRS	Unified Parkinson’s Disease Rating Scale

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Systematic lit: Neurodegenerative diseases and third wave therapies

Long title - The effectiveness of third wave therapies on neurodegenerative diseases

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The authors have no conflicts of interest to declare

1.0 Abstract

Objectives: Previous research has identified the effectiveness of third wave therapies in reducing the symptoms of a variety of physical and psychological presentations. This systematic review will assess the efficacy of third wave therapies for adults with neurodegenerative diseases.

Methods: The selected electronic databases, Medline, PsychInfo, Embase and Cinahl, were used to search for studies that were published from the inception of each database to January 2018. Third wave therapies (e.g. Acceptance and Commitment Therapy, Dialectical Behaviour Therapy, Mindfulness-Based Cognitive Therapy) and neurodegenerative diseases (e.g. Alzheimer disease, Parkinson's disease, Prion disease) were included as search terms.

Results: The systematic literature search revealed 570 potentially relevant papers. From this number, seven studies were found to be eligible for inclusion in the narrative synthesis. These studies reported on four neurodegenerative diseases and five adapted third wave therapy interventions. There were found to be mixed results on the effectiveness of third wave therapies for improving both physical and psychological symptoms in a variety of neurodegenerative diseases.

Conclusions: At this stage, it is not possible to deem whether third wave therapies are feasible in offering psychological or physical benefits to the neurodegenerative disease population. However, despite not being able to draw any firm conclusions, the use of third wave therapies has shown some potential benefits. Further randomised controlled trials to assess the effectiveness of adapted third wave therapies are required.

Practitioner Points

+ Three studies identified improvements in cognitive functioning in the intervention group in comparison with the control group.

+ Some studies also found improvements in anxiety, depression, quality of life, and mindfulness following third wave therapy interventions.

- However, an increase in depression, stress and a reduction in quality of life found following third wave therapies.

- As this is the first review of this population and third wave therapies, it has not been possible to focus more closely on just one specific third wave therapy or neurodegenerative disease. Further research on the effectiveness of third wave therapies in this population is required.

2.0 Introduction

2.1 Neurodegenerative disease

Neurodegenerative disease is an umbrella term for various degenerative conditions. The most common are Alzheimer disease, Parkinson disease, Lewy body dementia, Frontotemporal dementia. The etiology of neurodevelopmental diseases has been suggested to be the influence of environmental factors (e.g. exposure to toxins), genetic susceptibility (e.g. inheritance of genetic mutation) and ageing (Braak, Rüb, Gai, Del Tredici, 2003; Halliwell, 2006). The disease progression is irreversible, there is no cure, and available medical treatments can be very limited in their ability to slow down the gradual degeneration process (Carr, 2006; Weintraub, Comella & Horn, 2008).

The pathophysiological process of neurodegenerative disease development is due to proteins within neurons, which both exist within the central nervous system, mutating and deteriorating in their ability to function. The proteins do not repair themselves and cannot be replaced, which then progressively leads to the deterioration of the brain and the spinal cord (Bertram & Tanzi, 2005; Moussaud et al., 2014).

The principal deterioration characteristic of neurodegenerative diseases is dementia; a loss of neurocognitive functioning (e.g. memory, recall and reasoning) caused by structural changes to the brain. Alzheimer disease, which is characterised by a gradual global cognitive decline, is the most common form of dementia representing up to 70% of cases. The disease can cause a reduction in executive functioning skills, such as selective attention, planning and working memory (Carr, 2006; Bechara, Damasio, Damasio & Anderson, 1994; Bertram & Tanzi, 2005). Other symptoms commonly exhibited include language deficits (e.g. transcortical sensory aphasia,

paraphasia, anomic aphasia) and during the later stages of the disease, myoclonus (e.g. ticks and jerks) and seizures (Krauss & Mathews, 2003).

Parkinson's disease, regarded as the second most common neurodegenerative disease, is largely characterised by motor ability deterioration (e.g. tremors and rigidity). Parkinson's disease dementia is also characterised by cognitive deficits (e.g. memory and information processing skills), but in comparison to other dementias, it is one the least prevalent at approximately 2% of all dementia diagnoses (Carr, 2006; Bertram & Tanzi, 2005; Schoenberg & Scott, 2011).

Lewy body dementia is the second most common form of dementia behind Alzheimer disease. It potentially accounts for up to 15% of adults with dementia, but due to its pathological overlap with AD and PD dementia, it is often not possible to diagnose it until an autopsy is performed. Symptoms can consist of motor deficits similar to those exhibited in Parkinson disease, as well as visual and auditory hallucinations and cognitive deterioration (Bertram & Tanzi, 2005; Schoenberg & Scott, 2011).

In frontal lobe dementia, deterioration is also associated with language, personality and behavioural changes as the disease progression causes lesions on key areas such as the orbitofrontal cortex and the dorsolateral prefrontal cortex, areas which are associated with impulsivity and decision making (Torregrossa, Quinn, & Taylor, 2008). Personality changes have been found to be an exacerbation of a person's premorbid personality construct. Therefore, prior traits of anger, anxiety, or depression increase in severity and frequency as the neurodegenerative disease progresses.

The remaining neurodegenerative diseases (e.g. Prion disease, Motor neurone diseases, Huntington's disease) exhibit a variety of the above symptoms to differing levels of intensity and severity. Although similar in their symptomology, differentiations can be made between neurodegenerative diseases based on a person's functioning during deterioration (Schoenberg & Scott, 2011).

2.2 Psychological difficulties

Neurodegenerative diseases contribute to the development of psychological difficulties, as the frustrating and life changing symptoms, lead to a reduction of independence and quality of life. The burden on adults with neurodegenerative diseases and their families is substantial, as is the economic cost of care and support (Dowding, Shenton & Salek, 2006; Olesen, Gustavsson, Svensson, Wittchen, & Jönsson, 2012; Wimo, Jönsson, Bond, Prince, & Winblad, 2013).

The World Population Ageing report (United Nations, 2015) has estimated that in the next twelve years the number of adults over the age of 60 will grow by over 50%. With this growth, so to comes the need for increased physical and psychological support surrounding age related diseases.

A variety of psychological therapies with a cognitive (e.g. learning new strategies), emotional (e.g. communication of feelings) and behavioural (e.g. self-care) person-centred focus for adults with neurodegenerative diseases and their carers have been found to be successful in improving quality of life (Brooker & Latham, 2015; Molloy, 2016: Pinquart, & Forstmeier, 2012).

However, limited focus has been paid to the effectiveness and benefits of third wave therapies for adults with neurodegenerative diseases.

2.3 Third wave therapies

Third wave therapies include Dialectical Behaviour Therapy (DBT) (Linehan, 1993), Acceptance and Commitment Therapy (ACT) (Hayes, 2004), Mindfulness-Based Cognitive Therapy (MBCT) (Segal, Teasdale, Williams, Gemar, 2002) and Mindfulness-Based Stress Reduction (MBSR) (Kabat-Zinn, 2003). The characteristic that all third wave psychotherapies share is a focus on mindfulness and acceptance techniques, in which recognition, observation and acceptance of thoughts, feelings and situations occur, without an attempt to challenge or remove them. The aim instead is to increase a person's behavioural skills so they are more prepared and reflective when reacting to negative cognitive processes (Forman & Herbert, 2009).

The act of being mindful is achieved through a range of meditative practices including body scans, meditation of the breath and mindful movement. It has been found to be beneficial as a means of improving attentional control, affect regulation, body awareness, and changing perception of the self (Hölzel et al., 2011). There is also evidence to suggest that accepting and recognising both positive and negative experiences rather than avoiding them, is both physically and psychologically beneficial (Kuyken et al., 2010).

Third wave therapies have been introduced as a treatment for a variety of physical health problems (e.g. eating disorders), neurological (e.g. multiple sclerosis) and mental health problems, with National Institute for Health and Care Excellence (NICE) guidelines recommending the use of Mindfulness

Based Cognitive Therapy (MBCT) as a treatment for chronic depression (Hofmann, Sawyer, Witt & Oh, 2010; Kahl, Winter & Schweiger, 2012; Kristeller & Wolever, 2010; NICE, 2009; Simpson et al., 2014). Third wave therapies have also been used as a means to improve quality of life and well-being in non-clinical samples (Fisak & von Lehe, 2012).

2.4 Rationale

Previously conducted randomised controlled trials (RCT) have investigated the physical and psychological benefits that third wave therapies offer to individual neurodegenerative disease diagnoses. However, a comprehensive systematic review of third wave therapies for a variety of neurodegenerative disease diagnoses has not been completed, and would be a useful addition to the knowledge base.

Therefore, the purpose of the systematic review is to include and review any RCT's that use third wave interventions to improve outcomes in adults with a neurodegenerative disease. The aims are to: 1) examine the effectiveness of third wave therapies in improving outcomes in neurodegenerative diseases, 2) identify which third wave therapies have been used with which neurodegenerative disease diagnoses, 3) identify which third wave therapy shows the most beneficial outcomes, 4) assess the strength of the evidence for the benefit of third wave therapies for the neurodegenerative disease population, 5) establish any weaknesses in the studies reviewed, and any potential future research recommendations.

2.5 Objective

The systematic literature review aims to examine the effect of third wave therapies in improving physical and psychological outcomes, such as improved quality of life, ability to cope and management of symptoms, amongst adults with a neurodegenerative disease.

3.0 Methodology

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines and other systematic review guidelines (Dempster, 2011;

Jahan, Naveed, Zeshan, Tahir, 2016) were followed in designing, extracting data and reporting the review.

3.1 Eligibility criteria

Studies were included in the review if: 1) they investigated third wave therapy interventions for participants with a neurodegenerative disease of any severity, 2) they reported pre and post quantitative measures of psychological (e.g. emotional, cognitive, interpersonal or behavioural) or physical outcomes, 3) they included a comparison group of participants who did not participate in a third-wave therapy, including participants in a waiting-list/usual care control group, 4) the participants were adults, 5) the studies were reported in English.

3.2 Information sources and search methods

The selected electronic databases, Medline, PsychInfo, Embase and Cinahl, were used to search for studies that were published from the inception of each database to January 2018. The third wave therapies selected for inclusion in the review were in accordance with a recent meta-analysis of third wave cognitive and behavioural therapies (e.g. Acceptance and Commitment Therapy, Dialectical Behaviour Therapy, Mindfulness-Based Cognitive Therapy) (Dimidjian et al., 2016). The term “contextual cognitive behavioural therapy” was also included in the search as it had recently been identified as a new name for third wave therapy (Hayes, Villatte, Levin & Hildebrandt, 2011).

The neurodegenerative disease terms (e.g. Alzheimer disease, Parkinson’s disease, Prion disease) used for the search followed the diagnoses identified by the EU joint programme for neurodegenerative disease (JPND) (Joint programme for neurodegenerative disease, 2018). The “neurodegenerative

disease" and "third wave therapy" search terms were customised for each database and combined using the word "and". The results from each database were saved in RefWorks (ProQuest). The search strategy for each database is in appendix A.

3.3 Data collection process

Two authors reviewed (using the eligibility criteria), firstly, the title and abstract of all hits from the electronic search and, secondly, the full texts of any hits that were agreed to be eligible on the basis of the title/abstract screen. Relevant data was systematically extracted from the full articles, including methods, participant information, interventions and outcomes (table 1 and 2). All authors reviewed the data and disagreements were resolved through discussions. The inter-rater agreement rate was 95%, and this high level of agreement is supported by a Cohen's kappa value of 0.75, $p < .001$.

3.4 Quality assessment

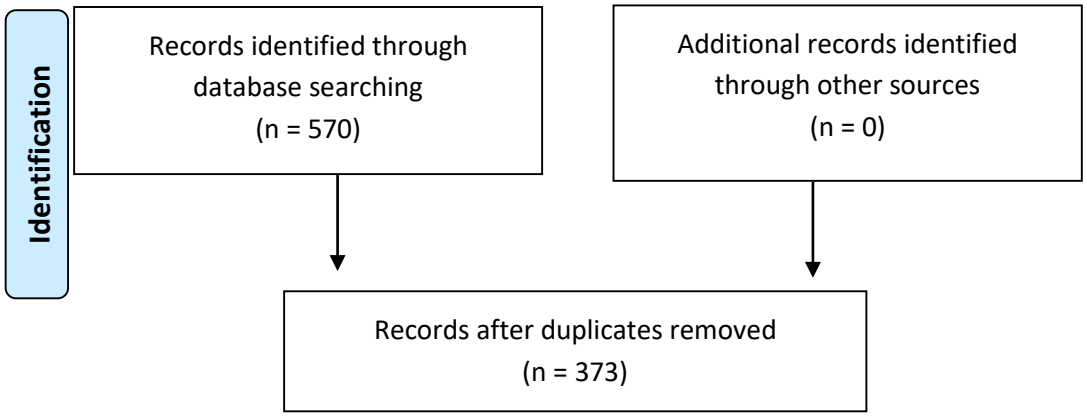
The quality of the studies was reviewed using the "Quality Assessment Tool for Quantitative Studies" (Effective Public Health Practice Project, 1998). For the review, the tool was used to synthesise knowledge about each study's quality (e.g. study design, blinding, intervention integrity) to produce an overall methodology rating of strong, moderate or weak (table 2).

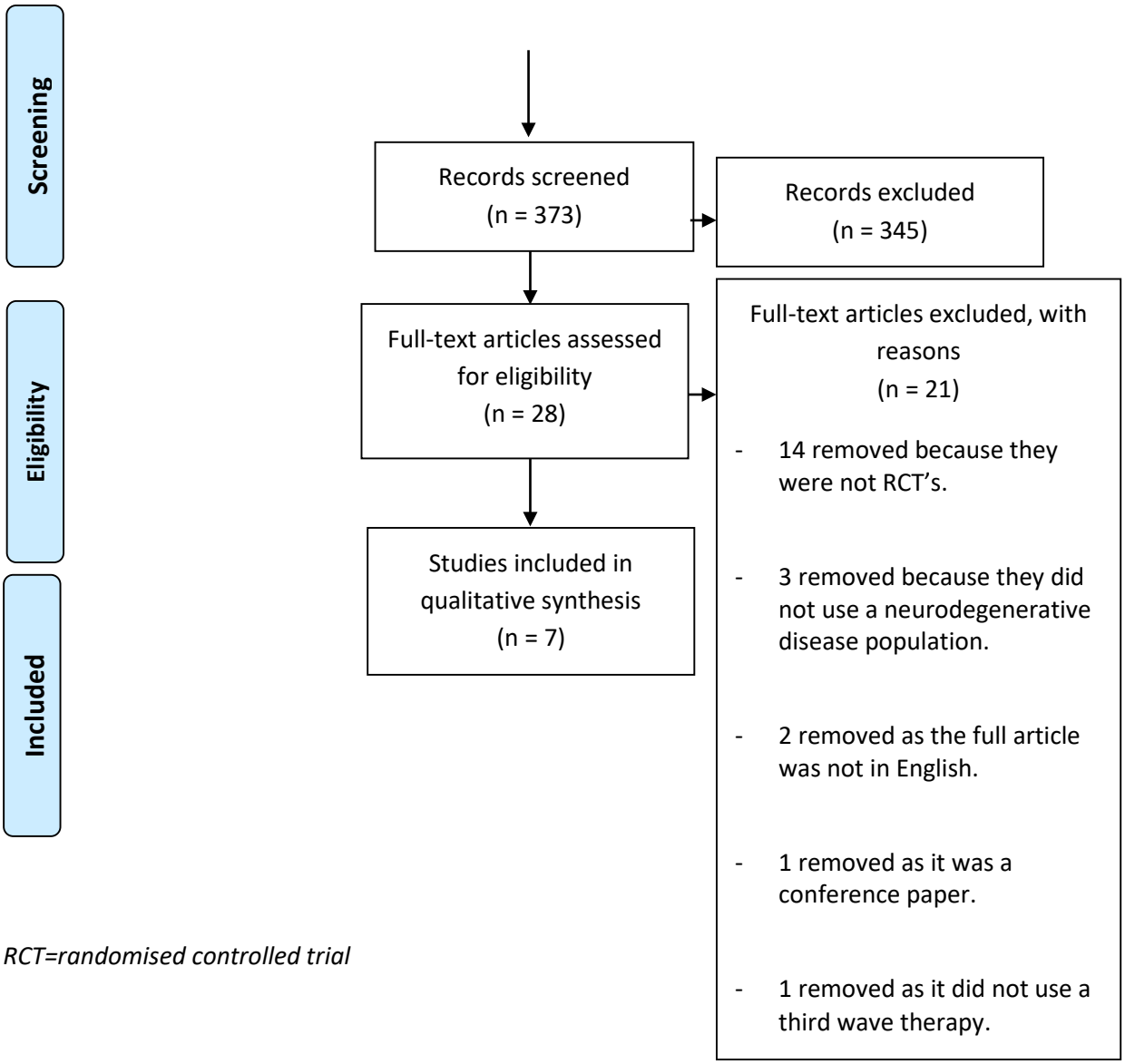
3.5 Analysis

A narrative synthesis was conducted due to the lack of homogeneity in the quantitative measures and interventions between the reviewed studies.

4.0 Results

Figure 1 – Study selection flow chart (from: Moher, Liberati, Tetzlaff, Altman, 2009) the PRISMA Group)





RCT=randomised controlled trial

4.1 Study selection

The systematic literature search revealed 570 potentially relevant papers. From this number, 197 duplicates were removed, leaving 373 titles and abstracts to be reviewed. From here, 345 papers were removed as they were not eligible, so that 28 papers received a full text screening, which led to the identification of 7 studies that were found to be eligible for inclusion in the narrative synthesis (figure 1). Out of the 7 studies included, two were

completed in Belgium, one in the Netherlands, one in Italy, one in Australia, one in England and one in Spain.

4.2 Study characteristics (table 1)

4.2.1 Population

Out of the seven studies included in the review, 474 participants were recruited, and the participants' average age ranged between 59 and 86 years old. The studies reported on four neurodegenerative diseases, of which, four studies investigated Parkinson's disease, one investigated Amyotrophic Lateral Sclerosis (ALS), one investigated Alzheimer's disease and one investigated Dementia.

The diagnosis requirement varied for each neurodegenerative disease; three of the four studies investigating participants from the Parkinson's disease population required a diagnosis according to the UK PD Brain Bank criteria, and the other Parkinson's disease study specified inclusion based on two questions that were designed by the authors of the study and a neurologist. Amyotrophic lateral sclerosis (ALS) was diagnosed according to El Escorial criteria, Alzheimer's disease was diagnosed in accordance with National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (NINCDS-ARDA) (McKhann et al., 1984) criteria and Dementia was diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV) (American Psychiatric Association, 1994) criteria.

4.2.2 Recruitment and intervention

Participants were recruited from outpatient clinics, a hospital setting, care homes, social services, and the Parkinson's disease community in a metropolitan city. One study did not state where they recruited participants from.

The studies reported on five adapted third wave therapy interventions for people with neurodegenerative diseases; three studies adapted Mindfulness-Based Stress Reduction (MBSR), one adapted both MBSR and Mindfulness Based Cognitive Therapy (MBCT), one used Mindfulness Based Alzheimer's Stimulation (MBAS), one adapted Acceptance and Commitment Therapy (ACT) and one adapted mindfulness techniques but didn't specify the mindfulness therapeutic approach. All studies offered group interventions that ran between one hour and two and a half hours, for a duration of between five weeks and two years.

The interventions were facilitated by experienced mindfulness teachers, a clinical psychologist trained as a meditation practitioner, two trainee clinical psychologists trained in MBSR, the author of an adapted mindfulness model and professionals from psychology, physical therapy and psychiatry. One study did not state who facilitated the intervention.

4.2.3 Control conditions

In six studies participants in the control groups received treatment as usual which consisted of physical group therapy in patients with PD, regularly scheduled visits to a movement disorders specialist or neurologist, individual counselling and psychological support when requested. In one study, the treatment as usual patients were offered MBI two months after the study.

Another study used a wait-list control group in which all participants eventually received the intervention, but only after the intervention group.

Three studies specified that participants follow stable medication schedules for the duration of the study, one study stated that all participants in the intervention and control group used Donepezil; a drug that improves cognition and behaviour in people with Alzheimer's disease. Three studies did not mention medication specifications.

4.3 Results of studies (table 2)

4.3.1 Anxiety

Four studies investigated anxiety as an outcome through the use of four different measures (BAI, HADS, DASS 21 & RAIDS). The results were mixed, as two studies found that the control group scores for anxiety increased more than the intervention group (Ghielen et al., 2017; Pagnini et al., 2017) and two studies did not find a difference between the intervention and control group (Advocat et al., 2016Churcher Churcher Clarke, Chan, Stott, Royan & Spector, 2017;).

4.3.2 Depression

Five studies investigated depression as an outcome through the use of four different measures (BDI, HADS, DASS 21 & CSDD). Mixed results were again found, with Ghielen et al., (2017) finding that depression increased in the intervention group more than in the control group at the three month follow up. Whereas, Pagnini et al., (2017) found that the control group experienced more of an increase in depression than the intervention group.

Three studies either found a trivial effect size or did not find any difference between the intervention group and control group (Advocat et al., 2016; Churcher Clarke et al., 2017; Pickut et al., 2015).

4.3.3 Quality of Life (QoL)

Five studies investigated QoL as an outcome through the use of three different measures (ALSSQOL, PDQ-39, QoL-AD). The results were once again mixed, with Ghielen et al., (2017) finding, over three time points, that the control group had a poorer quality of life than the intervention group, in four subtests. These subtests were, emotional wellbeing both at post intervention and at three month follow up, bodily discomfort at post intervention, and communication and activities of daily living at three month follow up. However, the intervention group also had a poorer quality of life than the control group in three subtests; stigma at post intervention and bodily discomfort and mobility at three month follow up.

Pagnini et al., (2017) and Churcher Clarke et al., (2017) found that the intervention group had a better quality of life than the control group. Whereas, Pickut et al., (2015) found that the intervention group experienced a poorer quality of life, on the pain subtest, than the control group.

Advocat et al., (2016) did not find a difference between the intervention group and control group in the total quality of life score.

4.3.4 Other outcomes – Stress, cognitive function, mindfulness and self-efficacy

Advocat et al., (2016) and Churcher Clarke et al., (2017) both found a small effect size, 0.32 and 0.28 respectively, that stress increased in the intervention group in comparison to the control group.

Three studies (Churcher Clarke et al., 2017; Pickut et al., 2013; Quintana-Hernandez et al., 2016) found improved cognitive functioning in the intervention group in comparison with the control group. The Churcher Clarke (2017) study found a small to medium effect size that suggests there was improved cognitive functioning in the intervention group. Also, the Pickut (2013) study found the intervention group showed significant changes in grey matter density in areas of the brain related to the pathophysiology of Parkinson's disease following the intervention.

Three studies looked at mindfulness and two found (Advocat et al., 2016; Pickut et al., 2015) an increase in mindfulness in the intervention group compared to the control group, with Advocat et al., (2016) identifying a medium effect size. However, Pagnini et al., (2017) did not find a difference in mindfulness between intervention and control groups over time.

Ghielen et al., (2017) also investigated self-efficacy and found there was no difference between the groups at post intervention, but that the control group had a small effect size increase in self-efficacy compared to the intervention group at the three month follow up.

4.4 Study quality

The "Quality Assessment Tool for Quantitative Studies" (Effective Public Health Practice Project, 1998) identified that two studies were of a strong quality, whereas five studies were of a moderate quality. Four studies (Advocat

et al., 2016; Churcher Clarke et al., 2016; Pickut et al., 2013; Quintana-Hernandez et al., 2016) had a weak selection bias, and one study (Pagnini et al., 2017) had a weak withdrawal rate, as several participants were forced to withdraw from the study because their health deteriorated or died. However, the withdrawal rate in the Pagnini (2017) study was forced due to death and illness.

4.5 Measurement

Where possible, Cohen's d statistic for the difference between groups in terms of the change from pre-test to post-test was calculated. These effect sizes were calculated using the formula presented by Morris (2008). Some studies did not present effect sizes and it was therefore not possible to calculate them with the data presented in the papers. The studies that did present effect sizes provided a comparison between the mean of the intervention group and the mean of the control group, to see how they differ by their standard deviations. It is suggested that 0.2 is a small effect size, 0.5 is a medium effect size and 0.8 is a large effect size.

5.0 Discussion

This narrative synthesis reviewed seven RCT studies for people with neurodegenerative diseases and found that third wave therapies, delivered in group settings, vary in their effectiveness in improving psychological wellbeing.

Out of the RCT studies available for this review, the quality of two of the studies was found to be strong and five were found to be moderate. This identifies that the studies offered generally robust evidence, but more studies are required to identify the long term benefit of third wave therapies.

Three studies found that the cognitive functioning outcome improved in the intervention group in comparison with the control group following third wave therapies. This is an interesting and potentially useful finding as it suggests that third wave therapies could assist in maintaining cognitive functioning, but one which requires further research.

In most outcomes, mixed results were found in both the intervention and control groups. Findings identified that the third wave therapy interventions showed positive improvements in anxiety, depression, quality of life, and mindfulness. However, it was also found that the interventions caused negative outcomes such as an increase in depression, stress and a reduction in quality of life suggesting that further research is required.

Mindfulness Based Cognitive Therapy (MBCT) has been recommended by the NICE guidelines for chronic depression (NICE, 2009). In this review, only one study (Churcher Clarke et al., 2017) looked at an adapted mindfulness-based cognitive therapy (MBCT) programme, finding a trivial effect size (d=0.06) for depression in the intervention group in comparison to the control group, following the treatment. Therefore, more research is required to assess whether MBCT reduces depression with a neurodegenerative disease population.

It is potentially the case that the intensified bodily focus involved in third wave therapy practices increases awareness of the symptoms of bodily discomfort experienced by people with neurodegenerative disease. Thereby, leading to an increase in the intervention group of participants reporting such issues as decreased mobility quality of life and increased stress levels.

However, this does not necessarily mean that the participants experienced an increase in their distress following third wave therapy, but potentially a better understanding and awareness of the already present neurodegenerative disease symptoms, which could potentially lead to a better awareness of their needs.

There were five aims of the review:

1) Examine the effectiveness of third wave therapies in improving outcomes in neurodegenerative diseases.

Any RCT study that analysed the effectiveness of third wave therapies with a neurodegenerative disease population was reviewed. However, due to the low number of studies and the variety of neurodegenerative disease populations, third wave therapies and outcomes analysed in each of the studies, it was not possible to thoroughly examine the effectiveness of third wave therapies in improving outcomes in neurodegenerative diseases.

2) Identify which third wave therapies have been used with which neurodegenerative disease diagnoses

Mindfulness-based lifestyle program, body awareness training (BEWARE) based on the principles of ACT, Mindfulness Based Intervention (MBI) closely following Mindfulness Based Stress Reduction (MBSR), and Mindfulness Based Intervention (MBI) closely following Mindfulness Based Stress Reduction (MBSR) were all used with a PD population. Meditation training based on Mindfulness-Based Stress Reduction (MBSR) was used with the Amyotrophic Lateral Sclerosis (ALS) population. Mindfulness Based Stress Reduction (MBSR) and Mindfulness-Based Cognitive Therapy (MBCT) were

used with a dementia population and Mindfulness Based Alzheimer's Stimulation (MBAS) were used with an Alzheimer's disease population.

3) Identify which third wave therapy shows the most beneficial outcomes

Again, because of the variability between studies, and limited number of RCT studies available, it is not possible to compare studies to clearly conclude that one third wave therapy shows the most beneficial outcomes.

4) Assess the strength of the evidence for the benefit of third wave therapies for the neurodegenerative disease population

The evidence that currently exists was assessed using narrative synthesis. It was concluded that the evidence is limited, as most of the studies looked at the Parkinson's disease population, and there were fewer studies looking at other neurodegenerative diseases. As well as this, it was found that studies looked at a variety of third wave therapies, so this limits the ability to review the effectiveness of each therapy. It was also found that there is not a standardised way of adapting third wave therapies, so this again limits the strength of the evidence, as comparisons between studies cannot be made.

5) Establish any weaknesses in the studies reviewed, and any potential future research recommendations.

As previously mentioned, the review was limited because there was substantial variability between each of the studies, in their populations, the therapies analysed, the treatment available to the control groups and the outcome measures used.

It is recommended for any potential future research to have a consensus on the measures that should be used when investigating the benefit of third wave therapies with this population. Therefore, consensus work should be done on appropriate outcomes for each diagnosis to allow for a clear comparison between studies. The Core Outcome Measures in Effectiveness Trials (COMET) (Prinsen et al., 2014) initiative have identified some outcomes for neurodegenerative diseases, but these have not been exclusively followed by the reviewed studies.

As well as this, based on the findings in this study, it might be useful for future research to focus on only one neurodegenerative disease. From the studies that were reviewed, four out of the seven studies used a Parkinson's disease population, so it might be beneficial for future studies to initially conduct research with this population to further improve the evidence base. Also, the findings in three of the studies, that cognitive functioning improves following third wave therapy in comparison to the control group, needs to be studied further and could be a focus of future research.

5.1 Limitations

As this is the first review of this population and third wave therapies, it has not been possible to focus more closely on just one specific third wave therapy or neurodegenerative disease, but such an approach will be beneficial in the future.

The review was limited because there was substantial variability between each of the studies, in their populations, the therapies analyed, the treatment available to the control groups and the outcome measures used.

The populations reviewed by the studies included four neurodegenerative diseases, of which, four studies investigated Parkinson's disease, one investigated Amyotrophic Lateral Sclerosis (ALS), one investigated Alzheimer's disease and one investigated Dementia. Therefore, because the development, progression and symptoms of each neurodegenerative disease are presented and experienced differently, it is difficult to make comparisons between each of these conditions.

Similarly, the reviewed studies reported on five adapted third wave therapy interventions for people with neurodegenerative diseases; three studies adapted Mindfulness-Based Stress Reduction (MBSR), one adapted both MBSR and Mindfulness Based Cognitive Therapy (MBCT), one used Mindfulness Based Alzheimer's Stimulation (MBAS), one adapted Acceptance and Commitment Therapy (ACT) and one adapted mindfulness techniques, but didn't specify the mindfulness therapeutic approach. Once again, based on the differences between the therapies, and the lack of consistency in their adaptation to suit the neurodegenerative disease they were treating, it was not possible to confidently state which therapy was the most effective.

As well as this, for the control groups, six of the studies offered treatment as usual which included a variety of physical group therapy, regularly scheduled visits to a movement disorders specialist or neurologist, individual counselling and psychological support when requested. In one study, the treatment as usual patients were offered MBI two months after the study. Another study used a wait-list control group in which all participants eventually received the intervention, but only after the intervention group. Therefore, there was substantial variability in the treatment offered to each control group, so it was

not possible to isolate standard variables. This made it difficult to clearly determine whether third wave therapies or control groups were influencing change in outcomes, and therefore limited the ability to identify the effectiveness of each therapy.

Finally, there were seven outcomes measured (e.g. anxiety, depression and quality of life) between the seven reviewed studies, with each study looking at a variety of these outcomes. Similar to the above mentioned limitations, this variety limited the comparisons that could be made between the studies, and therefore, restricted the interpretations and conclusions that could be made about the effectiveness of the third wave therapies.

During the review search, several relevant studies that were in the process of being completed were found, and as such their final findings will likely improve the current knowledge base regarding the benefits of third wave therapies for the neurodegenerative disease population.

5.2 Conclusions

At this stage, due to the lack of RCT studies available, and the substantial variability between the RCT studies that were reviewed, it is not possible to deem whether third wave therapies are an effective treatment for the neurodegenerative disease population.

Therefore, further research looking at third wave therapies and the neurodegenerative disease population is required. As well as this, it would be beneficial for third wave therapies to be adapted in a standardised way for this population. Research can then be replicated using the same standardised

therapeutic approach, to measure whether change occurs in comparison to a control group.

It would also be useful for future research to have a consensus on the outcome measures that should be used when investigating the effectiveness of third wave therapies with this population. Therefore, consensus work should be done on appropriate outcomes for each neurodegenerative disease, to allow for a clear comparison between studies

Table 1: Characteristics of the included studies

Study	Design	Setting	Diagnosis	Participants	Intervention	Control group
Advocat et al., (2016)	Design: RCT. Assessment points: Baseline, seven weeks and six months.	Recruited from PD community in metropolitan Melbourne, Austrailia. Located in two different inner-urban suburbs of Melbourne.	Hoehn and Yahr (H&Y) stage two Parkinson's disease screened by two questions developed by the authors and a neurologist.	No. of p'pants: Total=72. Mindfulness= 35. Control=37. Age: Mindfulness group = 62.8 average, Control group=63.7 average. Gender: Mindfulness group= female 66.7%. Control group= female 51.5%. Inclusion criteria: 1) aged 18 to 70, 2) Fluent spoken and written English, 3) Able attend at least four sessions, 4) Community living adults with disability congruent H&Y Stage 2 PD.	Mindfulness-based lifestyle program facilitated, two hour group sessions once a week for a total of 6-weeks. Two hour group sessions once a week for a total of 6-weeks. Facilitator: Both the program facilitator and the author of the adapted mindfulness model.	Wait-list control group - all participants eventually received the intervention, but only after the intervention group.
Churcher Clarke et al., (2017)	Design: RCT. Assessment points: Baseline and post-test.	Recruited from and study located in four care homes in England.	Dementia according to DSM-IV criteria.	No. of p'pants: Total=31. Mindfulness=20 & control=11. Age: Total=80.61 average. Mindfulness=81.30, Control=79.36 average. Gender: Total=48% female. Mindfulness= 60% female. Control= 11%female.	Adapted mindfulness programme guided by Mindfulness based stress reduction (MBSR) and mindfulness-based cognitive therapy (MBCT).	TAU

				Cognitive status: Mild and moderate dementia. Inclusion criteria: 1) Dementia 2) mild to moderate cognitive impairment, 3) capacity to give consent, 4) communicate verbally, 5) see and hear well enough to participate, 6) maintain concentration and remain in session, 7) speak English. Exclusion criteria: 1) had a major physical illness or disability that could impact participation, 2) had a diagnosis of learning disability, 3) were actively practising meditation or yoga or, 4) had a history of brain lesions or major head trauma.	Ten one hour group sessions, running twice a week for 5 weeks. Facilitator: Two trainee clinical psychologists, trained in MBSR.	
Ghielen et al., (2017)	Design: RCT, Assessment points: Baseline, post-treatment and 3 months after intervention completed.	Recruited from outpatient clinic in The Netherlands	PD according to the UK PD Brain Bank criteria	No. of p'pants: 19= Intervention, 19= treatment as usual. Age: ACT group= 59.6 average, control group= 66.6, Gender: Intervention group = 35% female, control group = 45% female, Cognitive status: no cognitive impairment (mini mental state examination), Inclusion criteria: 1) idiopathic PD 2) one or more wearing-off symptoms, 3) clinically relevant anxiety. Exclusion criteria: 1) Cognitive impairment, 2) insufficient motivation for participation, 3)	Body awareness training (BEWARE) based on the principles of ACT. 12 sessions, 1-hour long, 2 times per week for 6 weeks Facilitator: Professionals from psychology, physical therapy and psychiatry.	Treatment as usual (TAU) - physical group therapy in patients with PD.

				neurological, orthopaedic or cardiopulmonary problems that could interfere with participation.		
Pagnini et al., (2017)	Design: RCT, Assessment points: Baseline, post intervention, 6 months and 12 months.	Recruitment and location in hospital setting in Italy.	Amyotrophic lateral sclerosis (ALS) according to El Escorial criteria.	No of p'pants: 50=MBSR group, 50=usual care group. Age: MBSR group = 57.9 average, usual care group = 63.4 average. Gender: MBSR group, female = 38%, usual care group, female = 34%. Cognitive status: No significant cognitive impairment. Inclusion criteria: 1) ALS, 2) 18 years or older, 3) ALS Functional Rating Scale Revised score above 24, 4) ALS within 18 months, 5) ability to speak and understand. Exclusion criteria: 1) No secondary severe comorbidity, 2) significant cognitive and/or behavioural impairment, 3) history of psychiatric disorders.	Meditation training based on the original Mindfulness-Based Stress Reduction (MBSR) programme and tailored for people with ALS. 12 months study. Facilitator: Not stated.	TAU-individual counselling and psychological support when requested.
Pickut et al., (2013)	Design: RCT. Assessment points: Baseline (up to one month before) and at eight	Recruited from and study located in outpatient neurology clinic, Belgium.	PD according to the UK Brain Bank Criteria.	No. of p'pants: Total=30, MBI=15, control group=15. Age: Total=61.8 average, MBI=61.4 average, Control=62.2 average.	Mindfulness based intervention (MBI) closely following Mindfulness Based Stress reduction (MBSR).	TAU - patients were offered MBI two months after the study.

	weeks (after the intervention within one month).			Gender: Total=48% female, MBI= 50% female, Control=46% female. Cognitive status: lack of cognitive dysfunction. Inclusion criteria: 1) PD, 2) Hoehn & Yahr stage I–III, 3) lack of features suggestive of atypical parkinsonism, 4) exclusion of neuroleptics, 5) treated PD with medication and unlikely to be requiring anti-PD medication, 6) stable dose of all medications for 30 days, 7) lack of cognitive dysfunction, 8) no known unstable or life threatening disease, 9) no previous mindfulness training, 10) no contra indications for MRI scanning, 11) commitment to attend all eight MBI classes.	2.5 hour meetings on eight consecutive weeks. Facilitator: Two experienced mindfulness teachers	
Pickut et al., (2015)	Design: RCT, Assessment points: Baseline and after the 8-week training.	Study located in a clinic setting in Belgium	PD according to the UK PD Brain Bank criteria.	No. of p'pants: 14 =Intervention, 13 =usual care. Age: MBI= 61.4 average, usual care= 62.2 average. Gender: MBI= 50% female, usual care= 46% female, Cognitive status: lack of cognitive dysfunction, Inclusion criteria:1) PD, 2) Hoehn and Yahr stages I–III,3) lack of features suggestive of atypical parkinsonism,4) exclusion of neuroleptics,5) treated with PD medication and unlikely to require anti-PD medication,6) stable dose of medications	Mindfulness based intervention (MBI) closely following mindfulness based stress reduction (MBSR). 2.5 hours for 8 consecutive weeks and home practice. Facilitator: Two experienced mindfulness teachers.	TAU - regularly scheduled visits to a movement disorders specialist or neurologist.

				for 30 days prior, 7) lack of cognitive dysfunction,8) no known unstable or life threatening disease,9) no previous mindfulness training,10) commitment to attend all classes.		
Quintana-Hernandez et al., (2016)	Design: RCT. Assessment points: Baseline, 6, 12, 18, 24 months.	Recruited from Municipal social services, primary care. Study located in memory unit, Spain.	Alzheimer's disease in accordance with NINCDS-ARDA criteria.	No of p'pants: 85, MBAS = 42, Control = 43. Age: All participants range = 65 - > 86 Gender: total= 55% female. Cognitive status: Dementia diagnosis. Inclusion criteria: 1) AD, 2) dementia, 3) absence of other dementia diseases, 4) regional brain atrophy in volume loss of hippocampus, 5) entorhinal cortex or amygdala evidenced by MRI,6) early and significant episodic memory impairment including gradual and progressive change in memory function over six months, the episodic memory impairment can be isolated or associated with other cognitive change, 7) global deterioration scale 3, 4, or 5, living at home, 8) not attending other health service or using any other pharmacological treatment other than donepezil.	Treatment 1: Mindfulness Based Alzheimer's Stimulation (MBAS). Three weekly group sessions for 90 mins for two years. Facilitator: Clinical psychologist with five years' experience as meditation practitioner.	TAU

Table 2: Results – comparing psychological interventions vs control conditions

Study	Outcome measures	Results – means (SD)	Effect Size Intervention vs Control (Cohen's d)	Study quality	Comments
Advocat et al., (2016)	1) FMI [9] 2) PDQ-39[4] 3a) DASS 21-Depression[10] 3b) DASS 21-Anxiety[10] 3c) DASS 21-Stress[10]	*Intervention mean (SD):* 1) FMI – Baseline: 37.1 (8.2), 7 week change (95 % CI): 4.88 (1.95 to 7.80), 6 month change (95 % CI): 0.95(−1.91 to 3.82). 2) PDQ39 – Baseline: 22.2 (12.4), 7 week change (95 % CI): −0.54 (−3.41 to 2.32), 6 month change (95 % CI): −0.89 (−3.71 to 1.93). 3a) DASS-D – Baseline: 4.50 (5.22), 7 week change (95 % CI): 1.92 (0.201 to 3.63), 6 month change (95 % CI): 0.78 (−0.90 to 2.47). 3b) DASS-A – Baseline: 7.58 (4.79), 7 week change (95 % CI): 0.33 (−1.67 to 2.34), 6 month change (95 % CI): −0.26 (−1.79 to 1.27). 3c) DASS-S – Baseline: 8.78 (6.35), 7 week change (95 % CI): 2.17 (0.12 to 4.23), 6 month change (95 % CI): −1.0 (−2.89 to 0.89). *Control mean (SD):* 1) FMI – Baseline: 34.5 (8.8), 7 week change (95 % CI): −1.06 (−3.81 to 1.68). 2) PDQ39 – Baseline: 26.8 (17.5), 7 week change (95 % CI): −1.53 (−3.64 to 0.57).	*7 week effects change comparison between groups:* 1) FMI: 0.61 2) PDQ39: 0.06 3a) DASS-D: 0.12 3b) DASS-A: 0.14 3c) DASS-S: 0.32	Moderate	- TAU group received the intervention after the 7-week measures were collected for the intervention group. Therefore, for the 6 months scores, all participants completed intervention.

		3a) DASS-D – Baseline: 7.19 (7.83), 7 week change (95 % CI): 1.06 (−0.84 to 2.97). 3b) DASS-A – Baseline: 9.81 (7.56), 7 week change (95 % CI): −0.63 (−2.92 to 1.67). 3c) DASS-S – Baseline: 12.44 (9.65), 7 week change (95 % CI): −1.63 (−3.68 to 0.43).		
Churcher Clarke et al., (2017)	1) CSDD [11] 2) RAIDS [12] 3) QoL-AD [13] 4) MMSE [14] 5) PSS-13 [15]	*Intervention Mean (SD):* 1) CSDD- Baseline: 6.80 (4.35) and post 5.75 (4.05) 2) RAIDS - Baseline: 7.80 (5.63) and post: 5.50 (3.94). 3) QoL-AD- Baseline: 34.02 (4.24) and post 36.37 (4.27). 4) MMSE- Baseline: 15.85 (3.68) and post: 15.25 (4.35). 5) PSS-13 – Baseline: 20.33 (7.12) and post: 23.89 (7.59) *Control mean (SD):* 1) CSDD- Baseline: 7.88 (6.90) and post: 5.25 (4.62) 2) RAIDS - Baseline: 8.25 (5.52) and post: 5.88 (5.33) 3) QoL-AD- Baseline: 34.58 (4.69) and post: 32.79 (4.44) 4) MMSE- Baseline: 15.75 (4.27) and post: 13.50 (6.14) 5) PSS-13— Baseline: 22.50 (4.66) and post: 23.50 (4.04)	1) CSDD: 0.06, 2) RAIDS: 0.04, 3) QoL-AD: 0.82, 4) MMSE: 0.45, 5) PSS-13: 0.28	Moderate
Ghielen et al., (2017)	1) BDI [1] 2) BAI [2] 3) GSES [3] 4a) PDQ 39 - mobility [4] 4b) PDQ 39 - activities of daily living [4]	*Intervention Mean & SD:* 1) BDI – Baseline: 9.80 (7.63), post: 9.07 (6.01), follow-up: 10.47 (7.76). 2) BAI – Baseline: 40.47 (13.71) post: 35.69 (12.14) follow-up: 36.67 (9.85). 3) GSES – Baseline: 30.75 (5.70), post: 30.93 (3.56), follow-up: 31.57 (7.00). 4a) PDQ 39 mobility - Baseline: 38.55 (19.58), post: 37.50 (21.13), follow-up: 40.67 (21.35). 4b) PDQ 39 activities - Baseline: 36.57 (18.22), post: 32.78 (19.21), follow-up: 32.14 (19.30).	1) BDI – post: -0.11, follow-up: 0.39. 2) BAI – post: -0.42, follow-up: -0.12. 3) GSES – post: 0.02, follow-up: -0.27. 4a) Mobility – post: -0.08, follow-up: -0.28.	Strong

4c) PDQ 39 - emotional wellbeing [4] 4d) PDQ 39 - stigma [4] 4e) PDQ 39 - social support[4] 4f) PDQ 39 – cognitions [4] 4g) PDQ 39 – communication [4] 4h) PDQ-bodily discomfort [4]	4c) PDQ 39 emotional - Baseline: 32.02 (19.89), post: 26.94 (19.15), follow-up: 21.73 (19.35). 4d) PDQ 39 stigma - Baseline: 22.06 (18.89), post: 22.92 (21.48), follow-up: 19.17 (22.34). 4e) PDQ 39 social - Baseline: 24.48 (18.63), post: 21.11 (21.33), follow-up: 22.22 (18.00). 4f) PDQ 39 cognitions - Baseline: 34.38 (17.18), post: 33.33 (16.65), follow-up: 34.17 (17.66). 4g) PDQ 39 communication - Baseline: 27.19 (15.43), post: 26.67 (19.21), follow-up: 25.00 (16.96). 4h) PDQ 39 discomfort - Baseline: 44.30 (22.92), post: 42.86 (27.12), follow-up: 50.00 (30.37). *Control Mean & SD:* 1) BDI – Baseline: 12.30 (8.39), post: 12.44 (5.41), follow-up: 9.81 (8.52). 2) BAI – Baseline: 39.05 (9.23), post: 39.25 (9.43), follow-up: 36.69 (6.05). 3) GSES – Baseline: 28.50 (4.56), post: 28.56 (4.27), follow-up: 30.75 (4.78). 4a) PDQ 39 mobility - Baseline: 48.55 (19.01), post: 45.78 (18.18), follow-up: 45.00 (21.95). 4b) PDQ 39 activities - Baseline: 33.99 (17.14), post: 33.59 (20.44), follow-up: 34.64 (24.33). 4c) PDQ 39 emotional - Baseline: 40.28 (21.10), post: 40.10 (17.93), follow-up: 35.16 (15.95). 4d) PDQ 39 stigma - Baseline: 30.00 (16.91), post: 26.17 (20.18), follow-up: 30.08 (19.53).	4b) Activities – post: -0.18, follow-up: 0.28. 4c) Emotional – post: 0.23, follow-up: 0.24. 4d) Stigma - post: -0.25, follow-up: 0.16. 4e) Social - post: 0.07, follow-up: 0.03. 4f) Cognitions - post: 0.09, follow-up: 0.17. 4g) Communication - post: -0.01, follow-up: 0.34. 4h) Discomfort - post: 0.41, follow-up: -0.28.

		4e) PDQ 39 social - Baseline: 25.42 (18.82), post: 23.44 (17.80), follow-up: 23.81 (18.74). 4f) PDQ 39 cognitions - Baseline: 33.44 (17.36), post: 33.98 (17.53), follow-up: 36.33 (17.71). 4g) PDQ 39 communication - Baseline: 32.50 (22.28), post: 31.77 (19.77), follow-up: 36.98 (19.24). 4h) PDQ 39 discomfort - Baseline: 53.33 (24.24), post: 61.98 (16.38), follow-up: 52.08 (18.88).		
Pagnini et al., (2017)	1a) ALSSQOL[7] 1b) Negative emotion [7] 1c) People and environment [7] 1d) Intimacy [7] 1e) Religiosity [7] 1f) Physical [7] 1g) Bulbar [7] 2a) HADS - anxiety [8] 2b) HADS-depression [8] 3) FFMQ [6]	*Intervention mean & SD:* 1a) ALSSQOL (single-item scale) – Baseline: 5.77 (1.95) 1b) Negative emotion – Baseline: 5.93 (1.50) 1c) People and environment – Baseline: 7.33 (1.63) 1d) Intimacy – Baseline: 5.65 (2.17) 1e) Religiosity – Baseline: 5.42 (2.91) 1f) Physical – Baseline: 6.25 (2.15) 1g) Bulbar – Baseline: 6.77 (2.73) 2a) Anxiety – Baseline: 7.84 (3.22) 2b) Depression – Baseline: 5.86 (2.77) 3) FFMQ – Baseline: 3.62 (0.42) *Control mean & SD:* 1a) ALSSQOL (single-item scale) – Baseline: 5.77 (2.36) 1b) Negative emotion – Baseline: 5.70 (1.54) 1c) People and environment – Baseline: 7.34 (1.41) 1d) Intimacy – Baseline: 5.14 (1.74) 1e) Religiosity – Baseline: 5.37 (3.59)	No follow up scores are available, so effect sizes could not be calculated. Analyses indicate that control group experience increasing anxiety and depression and decreasing quality of life over time. The intervention prevents this deterioration.	Moderate

		1f) Physical – Baseline: 6.08 (1.91) 1g) Bulbar – Baseline: 6.12 (2.47) 2a) Anxiety – Baseline: 7.24 (3.66) 2b) Depression – Baseline: 6.36 (2.84) 3) FFMQ – Baseline: 3.51 (0.49).			
Pickut et al., (2013)	MRI examinations were performed on a 3 Tesla scanner	"MRI findings showed increased grey matter density (GMD) in the intervention group compared to the control group overtime in the left and right hippocampus and a small region in the right amygdala". However, "increased GMD was found in the control compared to the intervention group in the anterior lobe and dentate nucleus of the left cerebellum". Therefore, the study found the intervention group showed significant changes in GMD in areas of the brain related to the pathophysiology of Parkinson's disease, after eight weeks of mindfulness.	No mean and standard deviations available so effect sizes could not be calculated.	Moderate	-No means (SD) displayed. Morphometric (VBM) study demonstrating structural brain changes.
Pickut et al., (2015)	1) UPDRS [5] 2) FFMQ [6] 3) PDQ-39 [4]	*Intervention Mean:* 1) UPDRS motor III score - Baseline: 27.43, post: 21.93. 2) FFMQ observe facet - Baseline: 24.14, post: 27.29. 3) PDQ-39- pain score - Baseline: approx. 7.5, post: approx. 8.3 *Control Mean:* 1) UPDRS motor III score – Baseline: 27.92, post: 29. 2) FFMQ observe facet – Baseline: 23.69, post: 23.54. 3) PDQ-39- pain score – Baseline: approx. 8.0, post: approx. 7.3.	No standard deviations are available so effect sizes could not be calculated.	Strong	-Differences between intervention and control in 3 outcome scores. -The mean and SD for BDI and other UPDRS, FFMQ and PDQ 39 subscales and total scores,

					were not provided as there was no sig effects found.
Quintana-Hernandez et al., (2016)	1) MMSE [14] 2) CAMCOG [16]	*Mild-moderate AD intervention group mean (SD)* 1) MMSE - Baseline: 22.46(2.8), 6 months: 22.31(3.18), 12 months: 21.49 (3.46), 18 months: 21.66(3.34), 24 months: 20.86 (3.81). 2) CAMCOG - Baseline: 71.40(9.80), 6 months: 72.46(10.73), 12 months: 71.17(11.70), 18 months: 71.20(11.97), 24 months: 68.49(14.50). *Mild-moderate AD control group mean (SD)* 1) MMSE - Baseline: 21.60(2.42), 6 months: 19.80(3.57), 12 months: 18.12(3.90), 18 months: 15.56(5.15), 24 months: 14.12(5.11). 2) CAMCOG - Baseline: 66.84(7.93), 6 months: 60.12(10.03), 12 months: 52.08(15.53), 18 months: 48.76(16.35), 24 months: 41.32(17.17). *Moderate-severe AD intervention group mean (SD)* 1) MMSE - Baseline: 17.00(0.89), 6 months: 20.33(2.08), 12 months: 21.00(2.64), 18 months: 20.33(3.21), 24 months: 18.00(1.73). 2) CAMCOG - Baseline: 64.67(8.08), 6 months: 62.00(4.58), 12 months: 64.67(6.11), 18 months: 66.00(7.81), 24 months: 57.33(8.74). *Moderate-severe AD control group mean (SD)* 1) MMSE - Baseline: 16.00(0.93), 6 months: 16.38(4.47), 12 months: 16.38(3.93), 18 months: 14.38(7.89), 24 months: 11.29(5.25). 2) CAMCOG - Baseline: 50.63(5.32), 6 months: 50.13 (10.97), 12 months: 50.88(12.14), 18 months: 36.13(20.07), 24 months: 30.29(17.25).	The sample sizes for the mild-moderate intervention and control groups, and the moderate-severe intervention and control groups were not displayed. Therefore, the effect sizes for each group could not be calculated.	Moderate	

1) BDI= Beck Depression Inventory, 2) BAI= Beck Anxiety Inventory, 3) GSES =General Self-Efficacy Scale, 4) PDQ-39 = The Parkinson's Disease Questionnaire-39 5) UPDRS=Unified Parkinson's Disease Rating Scale, 6) FFMQ=Five Facet Mindfulness Questionnaire, 7) ALSSQOL-R=ALS-Specific Quality of Life Revised scale, 8) HADS= Hospital Anxiety and Depression Scale, 9) FMI=Freiburg Mindfulness Inventory, 10) DASS 21 = Depression Anxiety Stress Scales, 11) CSDD= Cornell Scale for Depression in Dementia, 12) RAIDS=Rating Anxiety in Dementia Scale, 13) QOL-AD= Quality of Life Alzheimer's Disease scale, 14) MMSE=Mini-Mental State Examination, 15) PSS-13= Perceived Stress Scale, 16) CAMCOG= Cambridge Cognition Examination

Effect sizes calculated using Cohen's d. It is suggested that 0.2 is a small effect size, 0.5 is a medium effect size and 0.8 is a large effect size.

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Technical Appendix

Appendix A – Search terms

Third wave therapies

Source: Considering Meta-Analysis, Meaning, and Metaphor: A Systematic Review and Critical Examination of “Third Wave” Cognitive and Behavioural Therapies Sona Dimidjian Joanna J. Arch Rebecca L. Schneider University of Colorado Boulder Philip Desormeau University of Toronto Scarborough Jennifer N. Felder University of California, San Francisco Zindel V. Segal University of Toronto Scarborough

- Acceptance and Commitment Therapy
- Dialectical Behaviour Therapy
- Mindfulness-Based Cognitive Therapy
- Functional Analytic Psychotherapy
- Behavioural Activation
- mindfulness
- metacognitive therapy
- schema therapy
- mode deactivation therapy
- integrative behavioural couple therapy
- compassionate mind training
- mindfulness-based stress reduction
- cognitive behavioural analysis system of psychotherapy
- mindfulness based training group

- positive psychotherapy
- Unified Protocol of Barlow
- compassion focused therapy
- “Contextual cognitive behavioural therapy,” – new name given by Hayes for third wave (Hayes, Villatte, Levin,& Hildebrandt, 2011).

Neurodegenerative diseases

Source: EU joint programme – neurodegenerative disease research

The neurodegenerative diseases that JPND focuses on are:

- Alzheimer’s disease (AD) and other dementias (Vascular dementia, Dementia with Lewy bodies, Frontotemporal dementia (Pick's disease), Creutzfeldt-Jakob disease).
- Parkinson’s disease (PD) and PD-related disorders
- Prion disease
- Motor neurone diseases (MND)
- Huntington’s disease (HD)
- Spinocerebellar ataxia (SCA)
- Spinal muscular atrophy (SMA)

Search strategy

Participant entries combined by “or”	Intervention entries combined by “or”
Participant and intervention entries combined by “and”	
1."Neurodegenerative disease".mp. or Neurodegenerative Diseases/ 2."Alzheimer's disease".mp. or Alzheimer Disease/ 3. "Vascular dementia".mp. or exp Dementia, Vascular/ 4. exp "Pick Disease of the Brain"/ or "Frontotemporal dementia".mp. or exp Dementia/ or exp Frontotemporal Dementia/ 5."Creutzfeldt-Jakob disease".mp. or exp Creutzfeldt-Jakob Syndrome/ 6.exp Parkinsonian Disorders/ or exp Parkinson	1. "Third wave".mp. 2. "Third-wave".mp. 3."Third wave therapies".mp. 4."Acceptance and commitment therapy".mp. or exp 5."Acceptance and Commitment Therapy"/ "Compassionate mind training".mp. 6. "Mindfulness-based cognitive therapy".mp. 7. "Dialectical behaviour therapy".mp. 8. "Dialectical behavior therapy".mp. 9."Metacognitive therapy".mp.

Disease/ or "Parkinson's disease".mp. 7. "Prion disease".mp. or exp Prion Diseases/ 8. exp Motor Neuron Disease/ or exp Motor Neurons/ or "Motor neurone diseases".mp. 9. exp Huntington Disease/ or "Huntington's disease".mp. 10."Spinocerebellar ataxia".mp. or exp Spinocerebellar Ataxias/ 11."Spinal muscular atrophy".mp. or exp Muscular Atrophy, Spinal/	10."Behavioural activation".mp. 11."Behavioral activation".mp. 12."Functional analytic psychotherapy".mp. 13."Integrative behavioral couple therapy".mp. 14."Mode deactivation therapy".mp. 15. "Schema therapy".mp. 16."Metacognitive therapy".mp. 17.(mindfulness or mindful).mp.

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Acknowledgements

I would like to express my sincere gratitude to Dr Martin Dempster and Dr Laura Thompson for their assistance and suggestions throughout the research project. I would also like to thank Peri Gillespie and Audrey Derby, from a UK gastroenterology charity, for their contribution. As well as this, I would like to say thank you to all the participants who took the time to share their experiences.

List of abbreviations

BIPQ	Brief Illness Perceptions Questionnaire
DSQ-28	Defense Style Questionnaire – 28
HRQoL	Health Related Quality of Life
IBD	Inflammatory Bowel Disease
IBDQ	Inflammatory Bowel Disease Questionnaire
REC	Research Ethics Committee (REC)
TAS – 20	Toronto Alexithymia Scale -20

LSRP: Defence styles, alexithymia, illness perceptions, and HRQOL in IBD

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The authors have no conflicts of interest to declare

1.0 Abstract

Background/aims: The role of psychological factors in the development and progression of Inflammatory Bowel Disease (IBD) is not completely understood. Several studies have suggested that defence styles, alexithymia and illness perceptions each individually influence the way a person experiences their disease, thereby impacting on health related quality of life (HRQoL). The study aimed to expand the knowledge base and assist in offering a better understanding of these variables.

Methods: The study employed a survey design and used opportunity sampling to recruit participants with IBD from a Regional Crohn's and Colitis support group and outpatient Gastroenterology clinics. Participants were given questionnaire packs containing measures and were asked to post them back to the researcher.

One hundred and thirty-nine participants were included in the study, of these 73.5% were female and 26.5% were males. 53.6% of participants reported being diagnosed with Crohn's disease, where as 41.3% were diagnosed with Ulcerative Colitis, 1.4% were diagnosed with both, and 3.6% had a diagnosis of IBD but did not have a clear diagnosis of either Crohn's or Colitis. The majority of participants identified that they were diagnosed with IBD between the ages of 20 and 29. Most participants (60.4%) felt that stress and worry was the cause of their IBD.

Results: The study found that defence styles, alexithymia and illness perceptions were all correlated with HRQoL. However, multiple regression analysis revealed that the alexithymia subtest, "difficulty identifying feelings"

and the neurotic defence style were the only variables that had a significant relationship with HRQoL. It was also found that females and people that were recently diagnosed also had a worse HRQoL.

Conclusion: These findings suggest that females who are recently diagnosed with IBD and have difficulty identifying feelings as well as a reliance on neurotic defence styles have a worse HRQoL. Therefore, screening of this population and the introduction of psychotherapy to assist with emotional care might be beneficial in improving HRQoL.

Practitioner Points

+ Gender, time since diagnosis, neurotic defence styles and difficulties identifying own emotional experiences found to potentially contribute to poorer HRQoL.

+ Therefore, therapy using emotional identification, especially when a person is just diagnosed, might be beneficial to people with IBD.

- The study used a cross sectional design, therefore it is not possible to infer causation. Future research should use a prospective design.

2.0. Introduction

2.1 Inflammatory Bowel Disease (IBD)

Inflammatory Bowel Disease (IBD) is an umbrella term used to describe a chronic inflammation of the digestive system, large intestine and the rectum. The most commonly diagnosed illnesses under the IBD umbrella are Ulcerative Colitis and Crohn's disease (Mawdsley and Rampton, 2006). Approximately, three hundred thousand people in the UK and three million people in Europe are currently diagnosed with IBD (Burisch, Jess, Martinato, & Lakatos, 2013).

IBD symptoms can be both physical (e.g. bloody diarrhoea, joint pain, and fever) and psychological (e.g. stress, anxiety and depression) (Neuendorf, Harding, Stello, Hanes, & Wahbeh, 2016; Sajadinejad, Asgari, Molavi, Kalantari, & Adibi, 2012). Due to both the physical and psychological symptoms, it is estimated that IBD costs society and the health care systems in Europe between 4.6 and 5.6 billion Euros per year (Burisch et al., 2013).

However, to date, emotional support for psychological symptoms has been limited, as psychoactive drugs are offered at a much higher rate than psychotherapy, despite psychotherapies, such as third wave therapy, being widely requested and shown to be effective for people with IBD (Tarricone et al., 2017). As such, recent research has focused on further understanding the psychological factors involved in managing the disease, with the hope of improving health related quality of life and reducing the economic burden. A recent systematic literature review of the psychological correlates in IBD found an association with neurotic defence styles, illness perceptions and

alexithymia with negative adjustment outcomes, namely quality of life (Jordan Sin, Fear, & Chalder, 2016).

2.2 Illness perceptions

A person's illness perceptions are influenced by their personal experiences and the information they hold about the illness, such as personal identity, the cause, the consequence and the curability of the illness (Leventhal, Nerenz, & Steele, 1984).

Previous studies have identified that illness perceptions can vary in people with IBD. Mussell, Böcker, Nagel, & Singer (2004) found that people with IBD tend to have illness perceptions that are either associated with responsibility for the outcome of the illness to themselves, others or fate. Other findings have identified that negative illness perceptions relating to social defamation and rejection, the social limits placed on a person due to the symptoms, and the concern of serious consequences, are related to poor HRQoL outcomes. As well as this, it was found that the perception of stigma felt by people with IBD can contribute to between 10 - 22% variance of their reported HRQoL (Dorrian, Dempster, & Adair, 2008; Faust, Halpern, Danoff-Burg & Cross, 2012; Kiebles, Doerfler & Keefer, 2010; Taft, Keefer, Leonhard & Nealon-Woods, 2009).

It has also been found that being positive about the ability to manage and care for personal symptoms is related to an increase in HRQoL in people with IBD (Munson, Wallston, Dittus, Speroff, & Roumie, 2009). This suggests that improving illness perceptions, can also improve HRQoL. However, to improve illness perceptions, a person's emotional protective processes must also be able to cope with the impact of the illness.

2.3 Defence styles

Studies on the role of defence styles in determining HRQoL within IBD populations have been limited; however, they suggest that certain defence profiles can have an impact. Hyphantis et al., (2010) found a significant positive correlation between IBD and immature defence profiles, namely maladaptive action and displacement. These defence styles are regarded as being socially undesirable, such as being passive aggressive, somatisation and retreating into fantasy. In particular, Hyphantis et al., (2005) demonstrated that Crohn's disease patients demonstrated higher levels of immature defence styles when compared to individuals with Ulcerative colitis.

Also, high rates of the immature defence style somatisation, which is a physical manifestation of emotional discomfort, is associated with a deprived HRQoL in people with IBD (Hyphantis et al., 2010). Whereas in contrast, IBD patients who adopted mature defence styles had lower relapse rates and surgical interventions. The mature defence styles, such as humility, mindfulness and forgiveness, are regarded as those that are displayed by emotionally healthy individuals.

Other studies have identified neurotic defence styles, which are regarded as being acceptable defences in the short term but not in the long term (e.g. repression, isolation and reaction formation), as being associated with poorer HRQoL of people with IBD (Barbera et al., 2017; Moreno-Jimenez et al 2007;). Interestingly, the neurotic defence style, reaction formation, which is to behave in a way that is the opposite of how a person wants or needs to behave, has

been independently associated with a poor HRQOL in people with IBD (Hyphantis, Tomensen, Bai & Creed, 2009).

Therefore, it is potentially the case that people with IBD struggle to manage the negative illness perceptions and emotions associated with their illness, such as stigma, rejection and shame. As a result, unhealthy defence styles are adopted that offer protection from acknowledgment and resolution of these negative emotions (Freud 1936; Vaillant, 1992).

2.4 Alexithymia

The potential reason that some people with IBD struggle to manage their negative emotions, is because they have difficulty identifying and describing them.

Alexithymia can be translated from Greek, to mean “without words for emotions” (Sifneos, 1996). It describes a person that is incapable of understanding or recognising their own feelings (Sifneos, 1996). Nemiah & Sifneos (1970) described patients that they believed had alexithymia as “seemingly detached, unconcerned, and distant”. Alexithymia has been found to be prevalent at a rate of between 5 -13% in the general population (Taylor, Bagby & Parker, 1997). However, it has been found to be prevalent at a higher rate in people with IBD (Iglesias-Rey et al, 2012; Moreno-Jiménez et al, 2007; Porcelli, Taylor, Bagby & De Carne, 1999).

Recent research has identified that alexithymia, along with defence styles, are related to severe physical conditions in females with IBD (Barbera et al, 2017). This finding is supported by previous research which suggests that alexithymia, specifically the subtests, “Difficulty identifying feelings” and

"externally oriented thinking" are associated with a low HRQoL in people with IBD (Iglesias-Rey et al., 2012). It has also been found that having a greater difficulty describing feelings is linked to a poorer HRQoL (Moreno – Jimenez, Blanco, Rodríguez-Muñoz & Hernández, 2007). As well as this, it has been suggested, that along with distress, alexithymia might have a significant effect on the symptomology of IBD (Filipovic & Filipovic, 2014).

It has been argued that the association might be explained by the difficulty that people with alexithymia have in recognising and regulating their own emotions. This inability to resolve the discomfort then manifests itself physically, which may be attributed to the IBD symptomology, and further contributes to a reduced HRQoL (Porcelli, Leoci, Guerra, Taylor, & Bagby, 1996; Porcelli, Zaka, Leoci, Centonze, & Taylor, 1995; Verissimo, Mota-Cardoso, & Taylor, 1998).

2.5 Rationale

Recent research has found that defence styles, specifically the neurotic defence style, alexithymia subtests, and illness perceptions are related to HRQoL in the IBD population regardless of disease activity. However, to date no studies have collectively looked at the variables to identify the extent of their relationship with HRQoL and which of these psychological variables is most strongly related to HRQoL in this context.

The findings will expand the knowledge base and assist in offering a better understanding of the variables that influence the HRQoL of people with IBD. The practical clinical benefit of the study is that it will assist in producing

empirical evidence that will inform future psychological interventions by assisting in identifying key variables.

2.6 Research question

What is the extent of the relationship between the predictor variables, defence styles, illness perceptions and alexithymia subtests, with the outcome variable, HRQoL?

3.0 Method

3.1 Participants

The study used opportunity sampling to recruit participants from an IBD charity and outpatient Gastroenterology clinic.

Inclusion criteria included both male and female participants from the age of 18 years old who had the ability to give consent and had sufficient English language comprehension to understand and complete the questionnaires. The participants had a diagnosis of Inflammatory Bowel Disease. The diagnosis and type of IBD was identified by participants on the demographic self-report form.

A sample size of 129 is sufficient to detect an R-squared value of at least 0.17 in a regression model with 14 predictors, with 90% power, using an alpha value of 0.05. As the regression model in this paper has an R-squared value of 0.45, the analysis has sufficient power.

3.2 Materials

3.2.1 Demographic self-report form (Appendix A)

The self-report form consisted of demographic and illness related information. It asked about gender, age, diagnosis, years since diagnosis and co-morbidity. The form attempted to capture any potential confounding variables. Confidentiality of data was ensured as personal details had not been requested from the participants.

3.2.2 Toronto Alexithymia Scale - TAS-20 (Bagby, Parker, & Taylor, 1994; Taylor, Bagby, & Parker, 1997)

The TAS - 20 is a 20 item self-report questionnaire of alexithymia. The measure consists of 3 sub-scales which include: difficulty identifying feelings, difficulty describing feelings, and an externally orientated thinking style. A score from 51 to 61 on the measure identifies “possible alexithymia”, where as a score above 61 suggests that a person has alexithymia. The TAS 20 has both a high test-retest reliability and internal reliability (Bagby, Parker & Taylor 1994; Bagby, Taylor & Parker, 1994).

3.2.3 The Brief Illness Perceptions Questionnaire -BIPQ (Moss-Morris, Weinman, Petrie, et al, 2002; Broadbent, Petrie , Main & Weinman, 2005)

The BIPQ is an eight item scale measure of illness perception that measures cognitive and emotional representation of illness perceptions. There is also a ninth item that allows for a qualitative response to be given.

The measure consists of an 11 point likert scale (0-10). It is designed to be prompt, valid and effective in large scale studies. The questionnaire can either produce a total overall score or it can produce sub scale scores (Karataş, Özen & Kutlutürkan, 2017). However, there is no standardised way of identifying the sub scale groups. The measure has good test-retest reliability and validity with relevant measures (Broadbent, Petrie, Main & Weinman, 2006).

3.2.3.1 BIPQ Subscales

Subscales have been suggested for the BIPQ, but the psychometric properties of these subscales have not been evidenced. Therefore, principal components analysis was conducted to determine whether any subscales are likely to exist within this sample. The analysis identified two components of the BIPQ; these were named “consequence focused” (i.e. questions 1-4) and “illness focused” (i.e. questions 5-8).

Questions in the “consequence focused” component (e.g. “How much does your illness affect your life?”) were closely related to the IBDQ outcome questions (e.g. “How often in the past 2 weeks have you had to delay or cancel a social engagement/ felt generally unwell/ tired and worn out/ unable to attend school or work/?”) and were therefore removed from analysis due to overlap. The “illness focused” component questioned a person’s perception of their illness (e.g. “How concerned are you about your illness?”) and was included in the analysis. Therefore, from here on all analysis excluded the “consequence focused” component of the BIPQ. A higher score on the illness focused sub-scale represents a more threatening perception of the illness.

3.2.4 Defense Style Questionnaire – DSQ-28 (Andrews, Singh, & Bond, 1993)

The Defense Style Questionnaire (DSQ-28) is a shortened version of the DSQ-40. The DSQ-40 was lacking in face validity and internal consistency on several items, so these items were removed and the DSQ-28 was created. It is a 28 item questionnaire with a 9 point likert scale ranging from “disagree strongly” to “strongly agree”. It assesses mature, neurotic and immature defence styles. With the removal of the items from DSQ-40, the measure was

found to have improved discriminant and criterion validity (Saint Martin, Valls, Rousseau, Callahan, & Chabrol, 2013).

3.2.5 Inflammatory Bowel Disease Questionnaire - IBDQ (Irvine, Zhou, & Thompson, 1996)

The IBDQ is a 32 item self-administered or interview administered measure of the health related quality of life (HRQOL) of people with IBD. The measure consists of four differing domains which include; bowel symptoms, emotional health, systemic systems and social function. The questionnaire produces scores on a range between 1-7, with 1 representing a poor HRQOL and 7 representing a good HRQOL. The IBDQ is a widely used instrument that has demonstrated its reliability and validity cross-culturally (Han, McColl, Steen, Barton, & Welfare, 1998; Pallis, Mouzas & Vlachonikolis, 2004).

3.3 Design and Statistical Analysis

The study employed a cross –sectional survey design. Exploratory analysis of the data identified that the variables met the required assumptions of normality and linearity for statistical analysis. Pearson product-moment correlation coefficient (r) was conducted to identify the strength of the relationship between the independent variables (defence styles, alexithymia and illness perceptions), and the dependent variable; health related quality of life.

Also, a multiple regression analysis was conducted to determine the amount of variance in HRQoL that is explained by the independent variables.

3.4 Procedure

Information and invitation sheets were displayed on the IBD charity website and in the newsletter (See appendix B). Questionnaire packs were then posted out to members of the IBD charity by the charity organisers to ensure confidentiality. Posters were also put up in the outpatient Gastroenterology clinic and a nurse gave out the application packs when requested by interested potential participants.

The questionnaire pack which contained the information sheet, one demographic self-report form and four questionnaires were returned by post, using the stamped addressed envelope, to the University, Psychology Department.

520 questionnaire packs were given out to participants, 420 through the IBD charity and 100 through the Gastroenterology clinic. 145 questionnaire packs were returned and 139 were eligible and used in the study.

The study was granted ethical approval by the NHS Research Ethics Committee (REC) and the local trust health board (See section 7).

4.0 Results

The relationship between the predictor variables, defence styles, illness perceptions and alexithymia subtests, with the outcome variable, HRQoL were measured using a correlation and multiple regression analysis.

4.1 Demographics

One hundred and thirty-nine participant questionnaire packs were included in the study. The majority of participants were female, with 73.5% of responses compared to 26.5% of males. Participants were most commonly aged between 30 and 49 years old and most people identified that they were diagnosed with the disease between the ages of 20 and 29. Crohn's Disease was the most common type of IBD identified, and 57% stated that they also had another medical condition. Most participants (60.4%) felt that stress and worry was the cause of their IBD (see table 1).

4.2 Measures

The illness focused perceptions mean score was found to be similar to other IBD population studies (Knowles, Cook, & Tribbick, 2013; Knowles, Gass, & Macrae, 2013). The Alexithymia mean score was found to be higher than the general population and other studies investigating IBD populations, suggesting higher levels of alexithymia (Barbera et al., 2017; Franz et al., 2007). For defence styles, the immature defence style was the most common response, similar to previous studies (Hyphantis et al., 2005). The HRQoL total score was found to be lower than in other IBD studies (Han et al., 1998; Pallis, Vlachonikolis & Mouzas, 2002), but higher than other findings (De Boer, Wijker, Bartelsman, & de Haes, 1995), suggesting a low quality of life (see table 2).

4.3 Correlation

A series of correlations were performed to examine the relationship between the predictor variables, defence styles, illness perceptions and alexithymia subtests, with the outcome variable, HRQoL. A significant relationship was found between each of the variables and HRQoL. The alexithymia subscale, "difficulty identifying feelings", had the strongest association, with a strong, negative and significant relationship with HRQoL (r = -0.54, p <0.001) (see table 3).

4.4 Multiple regression analysis

Multiple regression analysis was conducted to examine the relative strength of the relationship between demographic information, alexithymia, defence styles and illness perceptions (the covariates) with HRQoL (the outcome measure). A significant regression equation was found (F(14, 114) = 6.687, p=.000), with an R^2 of .451.

Overall, time since diagnosis (beta = 0.22, p= 0.018), gender (beta = 0.20, p= 0.009), difficulty identifying feelings (beta = -0.33, p= 0.003) and neurotic defence style (beta = -0.18, p= 0.041) were all statistically significant measures for explaining variance in HRQOL. Difficulty identifying feelings recorded the highest significant beta value out of all the contributors thereby identifying that it made the strongest unique contribution to explaining the total IBD HRQOL score. A total of 45.1% variance of HRQoL was explained by the model (see table 4).

5.0 Discussion

This study examined the extent that defence styles (mature, immature and neurotic), alexithymia subtests (difficulty identifying feelings, difficulty describing feelings and externally orientated thinking) and illness perceptions, are related to HRQoL in IBD.

It was found that all of the variables were significantly correlated to HRQoL. However, in the multiple regression analysis, only the alexithymia subtest, "difficulty identifying feelings" and the neurotic defence style had a significant relationship with HRQoL. From the demographic information, gender and time since diagnosis, were also both significantly related with HRQoL, suggesting that females and participants more recently diagnosed with IBD, have a worse HRQoL.

These findings are similar to those found in recent research which identifies that alexithymia, along with the neurotic defence style, are related to severe physical conditions in females with IBD (Barbera et al., 2017). In the study, it was suggested that females with alexithymia are more likely to develop IBD than males because females somaticize their emotional pain, whereas males with alexithymia develop behavioural issues. It has also been suggested that such difficulties associated with alexithymia might have a significant effect on the symptomology of IBD (Filipovic & Filipovic, 2014).

The association between the alexithymia subtest "difficulty identifying feelings" and poor HRQoL in people with IBD has also been found in previous research (Iglesias-Rey et al., 2012). It has been suggested that an individual's difficulty in effectively identifying their own feelings can limit their ability to differentiate between psychological experiences, such as anxiety, and IBD

symptoms. As a result, IBD symptoms may be interpreted as an emotional response or emotions may be interpreted as a symptom of IBD. Therefore, people who have “difficulty identifying feelings” might be more likely to somaticize psychological experiences such as emotional distress, and potentially experience them as physical pain (Barbera et al., 2017; Sifneos, 1996; Taylor, Bagby, & Parker, 1997).

The significant relationship between neurotic defence style and a poor HRQoL has been identified in previous research (Barbera et al., 2017; Jordan et al., 2016; Hyphantis et al., 2009; Moreno-Jimenez et al., 2007). The neurotic defence style includes thoughts and behaviours such as repression, isolation and denial which attempt to avoid the experience of painful emotions, such as shame and anxiety. Therefore, “difficulty identifying feelings” which may involve the misinterpretation of feelings, combined with more neurotic defence styles, can lead to an emotional detachment from the IBD symptoms and an inaccurate perception of the illness (Hyphantis et al., 2009; Moreno-Jimenez et al., 2007).

Illness perceptions have been identified as being important in the IBD population (Dorrian et al., Knowles et al., 2013; Rochelle & Fidler, 2013). However, for this study, the lack of a significant relationship between illness perceptions and HRQoL is potentially due to only a subtest of the BIPQ being investigated. Therefore, it is potentially the case that the inclusion of only the illness focussed perceptions, without the consequence focussed perceptions, distorted the relationship with HRQoL.

5.1 Future directions

A recent systematic literature review has identified that a small proportion of people with IBD have access to psychotherapy despite it being found to be effective in treating psychological issues (Tarricone et al., 2017).On the basis of this study, psychological interventions could be tailored to individual needs, and might benefit from focusing on emotion based psychoeducation to provide an in depth awareness and understanding of a person's abilities to recognise individual emotions, the purpose and function of emotions and the positive and negative connotations associated with each.

The Tarricone review (2017) also found that third wave psychotherapies that assist in developing a mind-body link are effective in improving adjustment outcomes. Such psychological therapy may contribute to encouraging a better awareness of emotional recognition and the importance of self-care in attempting to manage IBD as a chronic condition.

5.2 Limitations

It is theorised that Alexithymia has a multidimensional structure consisting of poor imagination, difficulty communicating feelings and difficulty recognising and identifying feelings. Due to these various dimensions, it is still not clear whether alexithymia can be measured by a single self-report assessment. It may be the case that a thorough assessment of all dimensions of alexithymia requires interviews with the participant and their family members. Therefore, to rely solely on a self-report assessment, in which participants have to be self-aware of whether they have a good imagination or can recognise other people's emotions, might result in participants not accurately reporting their

ability to do these things. Therefore, the measurement of alexithymia used in this study might not be accurate.

Also, a participant's mood at the time of completing the questionnaire might have influenced how illness perceptions, alexithymia, defence styles and alexithymia were reported. In the study we did not request to know the participants mood at the time of completing the questionnaire (e.g. anxiety measure). Therefore, a person who was feeling more anxious at the time of reporting might have also reported a lower HRQoL at the time.

Similarly, the participant's disease severity was also not requested as part of the questionnaire. Therefore, it is possible that the participants who were experiencing an active period of symptoms would have recorded a worse quality of life at this time. Whereas, participants who were not experiencing severe symptoms might have regarded their illness as manageable, which would have been reflected in the way illness perceptions, alexithymia, defence styles and HRQoL were reported.

5.3 Summary

These findings were similar to those recently found in the Barbera et al., (2017) study, suggesting that females who are recently diagnosed with IBD and have difficulty identifying feelings as well as a reliance on neurotic defence styles have a worse HRQoL. Therefore, it might be beneficial to conduct a screening at the time of diagnosis to identify this population and offer psychotherapy to assist with emotional care and long term HRQoL.

1 Table 1: Descriptive data for demographic information

Demographic information (total sample size – 139 participants)	N	Percentage
Age	138	
18 – 19	9	6.5%
20 – 29	22	15.9%
30 – 39	28	20.3%
40 – 49	28	20.3%
50 – 59	23	16.7%
60 – 69	23	16.7%
70 and above	5	3.6%
Gender	136	
Male	36	26.5%
Female	100	73.5%
Diagnosis	138	
Crohn's Disease	74	53.6%
Ulcerative Colitis	57	41.3%
Both	2	1.4%
Not clearly diagnosed with either	5	3.6%
Diagnosis age	138	
19 and below	39	28.3%
20 – 29	41	29.7%
30 – 39	27	19.6%
40 – 49	17	12.3%

50 – 59	10	7.2%
60 - 69	4	2.9%
Other medical conditions	138	
Yes	79	57.7%
No	57	42.3%
Anxiety or depression named as other medical condition	138	
Yes	20	14.4%
No	118	85.6%
Colostomy or ileostomy	139	
Yes	22	16.2%
No	114	84.8%
Perceived cause of IBD	139	
Stress or worry	84	60.4%
Hereditary or genes	54	38.8%
Diet or food	45	32.4%

Table 2: Descriptive data for illness factor, alexithymia, defence styles and HRQoL measures

Measures	N	Mean scores	SD
Illness factor subtest			
Total score	138	24.99	6.61
Alexithymia			
TAS-20 Subscale 1 (difficulty identifying feelings)	138	22.15	7.844
TAS-20 Subscale 2 (difficulty describing feelings)	138	15.14	4.785
TAS-20 Subscale 3 (externally oriented thinking)	138	21.19	5.340
TAS-20 Total Score	138	58.97	14.603
Defence styles			
Mature defence style total	137	43.05	11.09
Neurotic defence style total	137	28.65	8.69
Immature defence style total	137	57.98	15.60
HRQOL			
Total score	137	129.39	42.01

Table 3: Relationship between illness factor, alexithymia, defence styles as measured by HRQOL

Measures	HRQOL total
Crohns vs colitis	*r* = -0.12 *p* = 0.13
Unclear vs colitis	*r* = 0.01 *p* = 0.89
Both vs colitis	*r* = -0.16 *p* = 0.06
Gender	*r* = 0.14 *p* = 0.10
Age	*r* = 0.05 *p* = 0.54
Time since diagnosis	*r* = 0.14 *p* = 0.10
Other medical conditions	*r* = 0.17 *p* = 0.04
Illness factor subscale	*r* = -0.26, *p* =0.002
Alexithymia TAS-20 Subscale 1 (difficulty	*r* = -0.54, *p* =0.00

identifying feelings)	
TAS-20 Subscale 2 (difficulty describing feelings)	*r* = -0.45, *p* =0.00
TAS-20 Subscale 3 (externally oriented thinking)	*r* = -0.22, *p* =0.00
Mature defence style total	*r* = 0.21, *p* = 0.02
Neurotic defence style total	*r* =-0.23, *p* =0.00
Immature defence style total	*r*=-0.22, *p* =0.00

Table 4: Multiple regression analysis for illness factor, alexithymia, defence styles with HRQoL total outcome score

Measures	Beta	Sig
Crohns vs colitis	-0.16	0.06
Unclear vs colitis	-0.03	0.63
Both vs colitis	-0.07	0.29
Gender	0.20	0.00
Age	-0.17	0.08
Time since diagnosis	0.22	0.01
Other medical conditions	0.11	0.13
Difficulty identifying feelings	-0.33	0.00
Difficulty describing feelings	-0.15	0.19
Externally orientated thinking	-0.02	0.80
Mature defence style	0.12	0.19
Neurotic defence style	-0.18	0.04
Immature defence style	0.06	0.45
Illness perceptions-	-0.06	0.46

illness focussed subscale		

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Technical appendix - Appendix A

Demographics form

Please respond to each item by checking it and/or writing your answer in the space provided

1. Age? _____

2. Gender?

Male ○

Female ○

3. Are you diagnosed with…

Ulcerative Colitis ○

Crohn's disease ○

Not clearly diagnosed with either ○

4. What age were you when you were first diagnosed with inflammatory bowel disease?

_____

5. Do you have any other medical conditions?

Yes ○

No ○

Please state…….

Appendix B

Invitation letter

Dear Sir or Madam,

Crohn's and Colitis UK (NI group) is collaborating with the School of Psychology at Queen's University Belfast to conduct research on Inflammatory Bowel Disease. As a member of Crohn's and Colitis UK (NI group), you have

received this letter of invitation to offer you the opportunity to participate in this research project.

Before you decide to take part in this study, it is important that you understand the purpose of the research study and what it involves for you. Please read carefully the information sheet on the following pages, and discuss it with friends and relatives if you like.

There are also contact details for the researchers that are involved in the study at the bottom of the information sheet. Please contact them if there is anything that is not clear, or if you would like more information about the research project. They will be glad to offer any further information on the study.

The Crohn's and Colitis UK (NI group) will deliver the questionnaire pack to your home by post in the coming weeks. If you would like to take part, please complete the questionnaire pack and return it to us using the free-post stamped addressed envelope provided.

Crohn's and Colitis UK (NI group) will not know whether or not you participated in the study, so please rest assured that your decision will not impact on the support provided to you by the group.

Yours faithfully,

Liam Reilly

(Lead researcher)

Thank you for your time.

Information about the study

We would like to invite you to take part in our research study. Before you decide if you would like to take part we would like you to understand why the research is being done and what it would involve for you. Please take the time to go through this information sheet. Crohn's and Colitis UK (NI group) will be sending out the questionnaire pack for you to complete in the coming weeks.

What is the research about?

Living with a chronic Illness such as Inflammatory Bowel Disease (IBD) can at times be difficult. Different people cope in different ways with the challenges of living with such a physical health problem. It is important to understand the various coping mechanisms that can impact on quality of life when living with IBD. Such an understanding would inform treatments that might be beneficial in the future.

Aims of the Study:

We are interested in exploring how various psychological coping mechanisms can impact on Quality of Life for individuals living with Crohn's Disease or Ulcerative Colitis.

Why have I been chosen?

You have been invited to take part in this study because you have a diagnosis of either Crohn's or Ulcerative Colitis and are aged 18 years or over. Other individuals who are in a similar position have also been invited to take part.

Do I have to take part?

Your participation in this study is voluntary. It is your decision to complete the questionnaire pack or not. If you decide not to complete and return the pack you will not be contacted by the researchers again.

What will I need to do?

You will be asked to complete a short questionnaire and return the questionnaires to the Psychology Department at Queens University in the free-post stamped addressed envelope provided. You will not have to answer any questions you do not want to. If you want to ask any questions about any of the questionnaires or the study, please contact any of the research team. The questionnaire will take approximately 25 minutes to complete.

Will the information I give be confidential?

All information will be treated confidentially and stored securely on a password protected computer and will be accessed by the research team. Results from this study will be presented on a group basis rather than specific individuals, so your information will not be identifiable.

What are the possible benefits of taking part in the research?

There are no direct benefits for you but people that take part in research studies generally think of it as a positive experience. It can provide a chance for you to get your experiences across and help inform service development.

Is there any risk involved in taking part in the research?

We do not expect that there will be any risks related to taking part in this study. However we are aware that sometimes talking about our experiences can be difficult but there are no known risks to taking part in this study. If someone did become upset or worried as a result of taking part we would like them to contact the research team so that support could be provided.

What happens with the research?

Information will be collected, anonymised and entered into a password-protected computer, ensuring all information remains confidential. Only the research team will have access to this information. The final report will be submitted to Queen's University, Belfast. We also hope to publish the results of this study in a scientific journal and present findings to health professionals. If you take part in this study and would like a summary copy of the findings we would be happy to send you a copy when the summary has been completed.

What happens next?

The questionnaire pack will be sent out to your home in the coming weeks by the Crohn's and Colitis UK (NI group). If you would like to take part, please complete the questionnaire pack and return it to us using the free-post stamped addressed envelope provided.

Research team contact details:

Liam Reilly (Lead Researcher)
Trainee Clinical Psychologist
Queens University Belfast
lreilly06@qub.ac.uk

Dr Martin Dempster
Health Psychologist / Chartered Statistician, and Director of Education
Tel: 028 9097 5652
m.dempster@qub.ac.uk

Dr Laura Thompson
Clinical Psychologist
Tel: 028 90632025
laura.thompson@belfasttrust.hscni.net

Alternative independent support phone numbers:

Crohn's and Colitis
Emotional support Tel: 0121 737 9931
info@crohnsandcolitis.org.uk

British Journal of Clinical Psychology
The British Psychological Society

Author Guidelines

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

All papers published in The British Journal of Clinical Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

The following types of paper are invited:

• Papers reporting original empirical investigations

• Theoretical papers, provided that these are sufficiently related to the empirical data

• Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications

• Brief reports and comments

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

The word limit for papers submitted for consideration to BJCP is 5000 words and any papers that are over this word limit will be returned to the authors. The word limit does not include the abstract, reference list, figures, or tables. Appendices however are included in the word limit. The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length. In such a case, the authors should contact the Editors before submission of the paper.

3. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. The Journal operates a policy of anonymous (double blind) peer review. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review to avoid unnecessary delays. Before submitting, please read the terms and conditions of submission and the declaration of competing interests. You may also like to use the Submission Checklist to help you prepare your paper.

4. Manuscript requirements

• Contributions must be typed in double spacing with wide margins. All sheets must be numbered.

• Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. You may like to use this template. When entering the author names into Editorial Manager, the

corresponding author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the Project CRediT website for a list of roles.

• The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and refer to any previous work in the third person.

• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.

• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

• All papers must include a structured abstract of up to 250 words under the headings: Objectives, Methods, Results, Conclusions. Articles which report original scientific research should also include a heading 'Design' before 'Methods'. The 'Methods' section for systematic reviews and theoretical papers should include, as a minimum, a description of the methods the author(s) used to access the literature they drew upon. That is, the abstract should summarize the databases that were consulted and the search terms that were used.

• All Articles must include Practitioner Points – these are 2–4 bullet points to detail the positive clinical implications of the work, with a further 2–4 bullet points outlining cautions

or limitations of the study. They should be placed below the abstract, with the heading 'Practitioner Points'.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.

• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

• In normal circumstances, effect size should be incorporated.

• Authors are requested to avoid the use of sexist language.

• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manualpublished by the American Psychological Association.

If you need more information about submitting your manuscript for publication, please email Vicki Pang, Editorial Assistant (bjc@wiley.com) or phone +44 (0) 1243 770 410 (ex 434 10).

5. Brief reports and comments

These allow publication of research studies and theoretical, critical or review comments with an essential contribution to make. They should be limited to 2000 words, including references. The abstract should not exceed 120 words and should be structured under these headings: Objective, Method, Results, Conclusions. There should be no more than one table or figure, which should only be included if it conveys information more efficiently than the text. Title, author name and address are not included in the word limit.

6. Supporting Information

BJC is happy to accept articles with supporting information supplied for online only publication. This may include appendices, supplementary figures, sound files, videoclips etc. These will be posted on Wiley Online Library with the article. The print version will have a note indicating that extra material is available online. Please indicate clearly on submission which material is for online only publication. Please note that extra online only material is published as supplied by the author in the same file format and is not copyedited or typeset. Further information about this service can be found at http://authorservices.wiley.com/bauthor/suppmat.asp

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11. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following web
site: http://www.adobe.com/products/acrobat/readstep2.html.

This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

12. Early View

British Journal of Clinical Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of

their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. E.g., Jones, A.B. (2010). Human rights Issues. *Human Rights Journal*. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x

Further information about the process of peer review and production can be found in this document: What happens to my paper? Appeals are handled according to the procedure recommended by COPE.

London - Riverside Research Ethics Committee
Level 3 Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0207 104 8037

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

14 November 2016

Mr Martin Dempster
School of Psychology, David Keir Building
18-30 Malone Rd
Belfast
BT9 5BN

Dear Mr Dempster

Study title:	**Illness perceptions, defence styles, alexithymia and health-related quality of life in people with inflammatory bowel disease: testing a mediator model**
REC reference:	**16/LO/2080**
IRAS project ID:	**216902**

The Proportionate Review Sub-committee of the London - Riverside Research Ethics Committee reviewed the above application on 16 November 2016.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Tina Cavaliere, nrescommittee.london-riverside@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion
On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion").

Approved documents

The documents reviewed and approved were:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of indemnity]		05 August 2016
IRAS Checklist XML [Checklist_10112016]		10 November 2016
Letter from sponsor [Sponsor letter]		05 August 2016
Letters of invitation to participant [Invitation letter]	1	05 August 2016
Non-validated questionnaire [Demographics form]	1	05 August 2016
Other [Validated questionnaire 2: The Brief Illness Perceptions Questionnaire – BIPQ]	1	05 August 2016
Other [Validated questionnaire 3: Defense Style Questionnaire – DSQ -28]	1	05 August 2016
Other [Validated questionnaire 4: Inflammatory Bowel Disease Questionnaire – IBDQ]	1	05 August 2016
Participant information sheet (PIS) [Information sheet]	Version 1	05 August 2016
REC Application Form [REC_Form_10112016]		10 November 2016
Referee's report or other scientific critique report [Research panel report]		05 August 2016
Research protocol or project proposal [Project proposal 5.8.16 version 1]	1	05 August 2016
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		05 August 2016
Summary CV for student [Student CV]		05 August 2016
Summary CV for supervisor (student research) [PI CV]		05 August 2016
Validated questionnaire [Toronto Alexithymia Scale - TAS-20]	1	05 August 2016

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

16/LO/2080	**Please quote this number on all correspondence**

Yours sincerely

Pp
Dr Margaret Jones
Chair

Email: nrescommittee.london-riverside@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

"After ethical review – guidance for researchers"

Copy to: *Ms Paula Tighe*
Ms Alison Murphy, Research & Development Office

London - Riverside Research Ethics Committee

Attendance at PRS Sub-Committee of the REC meeting on 16 November 2016

Committee Members:

Name	*Profession*	*Present*	*Notes*
Miss Stephanie Ellis	Former Civil Servant	Yes	
Dr Margaret Jones (Chair)	Retired General Practitioner	Yes	
Ms Julia Williams	Senior Producer	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Tina Cavaliere	REC Manager

Belfast Health and Social Care Trust

caring supporting improving together

22/02/2017

Mr Martin Dempster
Post Senior Lecturer
School of Psychology, Queen's University Belfast
David Keir Building
18-30 Malone Road
Belfast
BT9 5BN

Dear Mr Dempster

Study Title: Illness perceptions, defence styles, alexithymia and health-related quality of life in people with inflammatory bowel disease: testing a mediator model
HSC Trust Ref: 16113MD-AS (Please quote this in all future correspondence)

REC Ref: 16/LO/2080
IRAS Ref: 216902

I am pleased to advise that Belfast HSC Trust has given final Research Governance Permission for the above project to commence. Permission is granted for the duration of the project to 01/02/2019.

The following documents have been approved for use in the project:

Document	Version	Date
Letters of Invitation to Participant [Invitation Letter]	1	05/08/2016
Non-Validated Questionnaire [Demographics Form]	1	05/08/2016
Other [Validated Questionnaire 2: The Brief illness Perceptions Questionnaire – BIPQ]	1	05/08/2016
Other [Validated Questionnaire 3:Defense Style Questionnaire-DSQ-28	1	05/08/2016
Other [Validated Questionnaire 4: Inflammatory Bowel Disease Questionnaire – [IBDQ]	1	05/08/2016
Participant Information Sheet (PIS) [Information Sheet]	1	05/08/2016
Research Protocol or Project Proposal [Project Proposal 5.8.16 version 1]	1	05/08/2016
Validated Questionnaire [Toronto Alexithymia Scale – TAS-20]		05/08/2016

The following personnel have been approved to work on the study at this Trust:

Name	Indemnity Provided by
Mrs Laura Thompson	BHSCT
Ms Evelyn Warwick	BHSCT
Professor Brian Johnston	BHSCT
Mr Liam Reilly	QUB

Permission is granted subject to the attached conditions and I would ask you to please ensure that all members of the research team are familiar with these. Failure to abide by these conditions will invalidate permission and may result in the cessation of the research.

I wish you every success with your project.

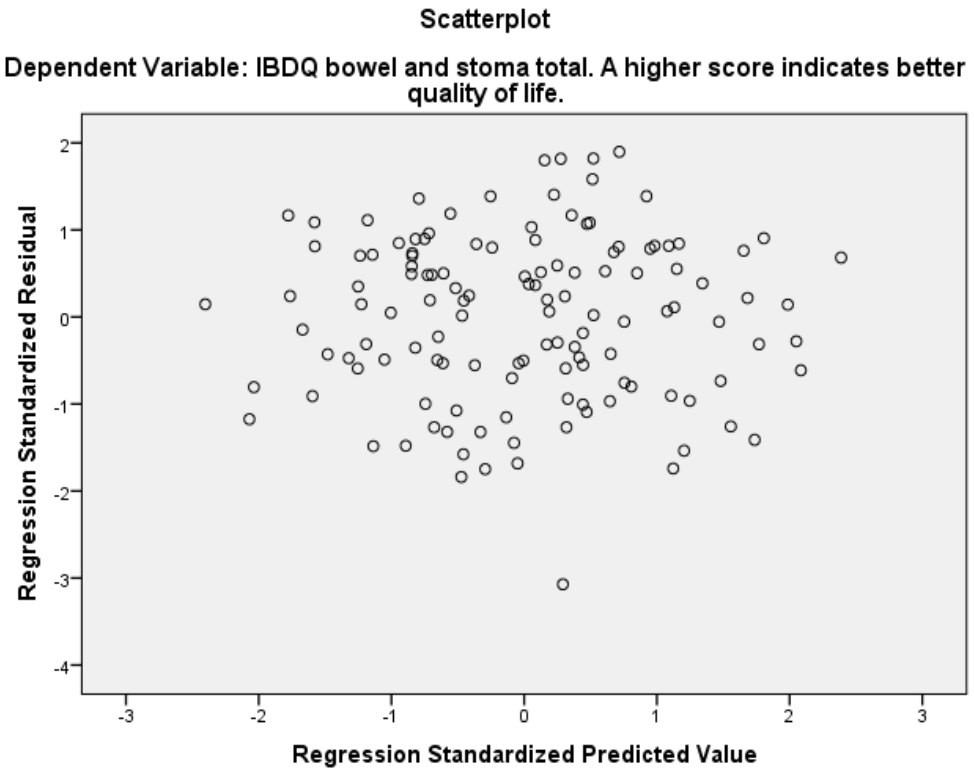
Yours sincerely,

Professor Ian Young
R&D Director

Cc: Laura Thompson,
Liam Reilly,
Karen Hodgen

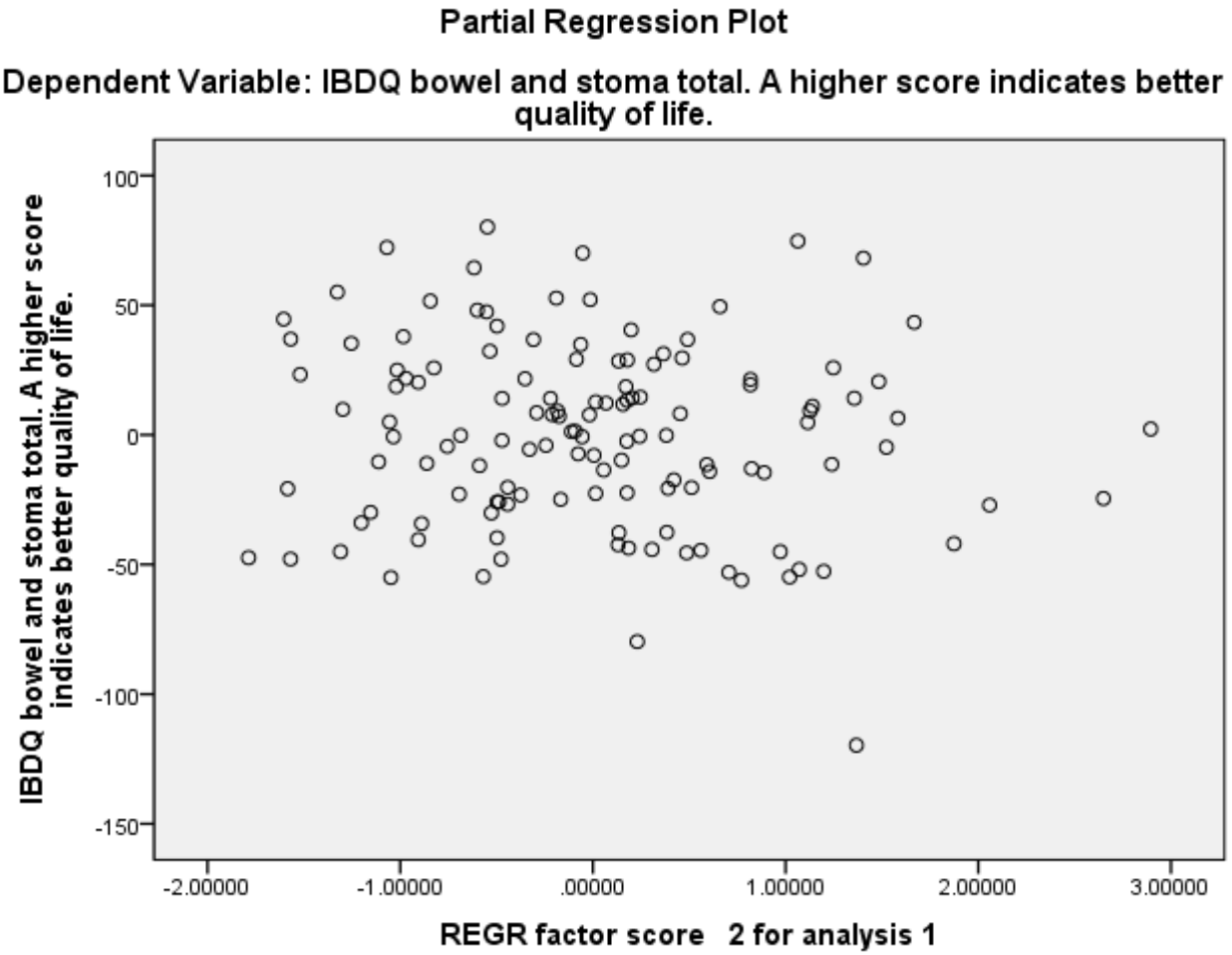
Multiple Linear Regression Assumptions

The plot tests the assumption of heteroscedasticity. The fact that there is no obvious pattern of points on the plot indicates that this assumption is met.

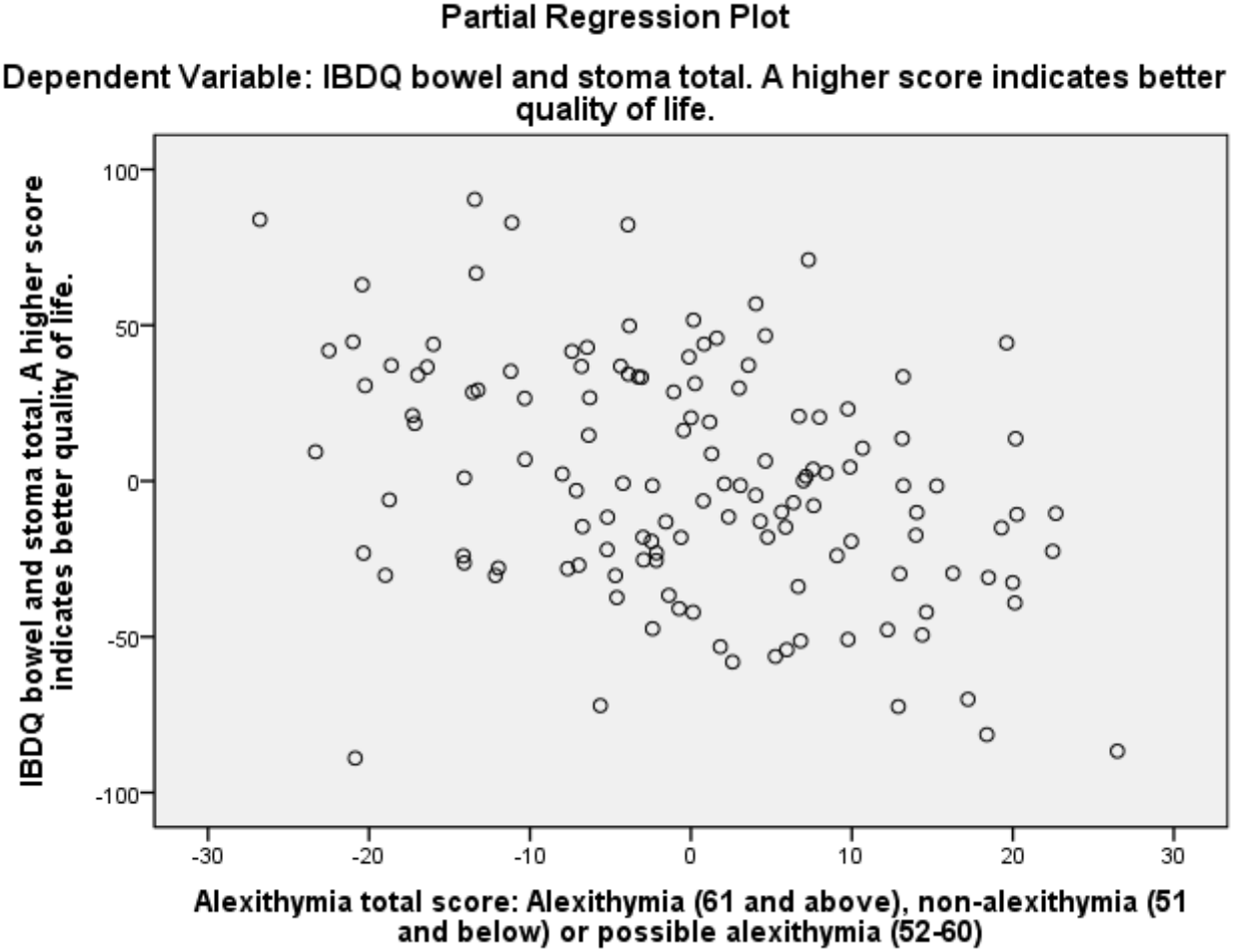


To test the assumption of linearity, partial regression plots were presented. The assumption is met as the pattern of points look like a random scatter, and do not look like a curve.

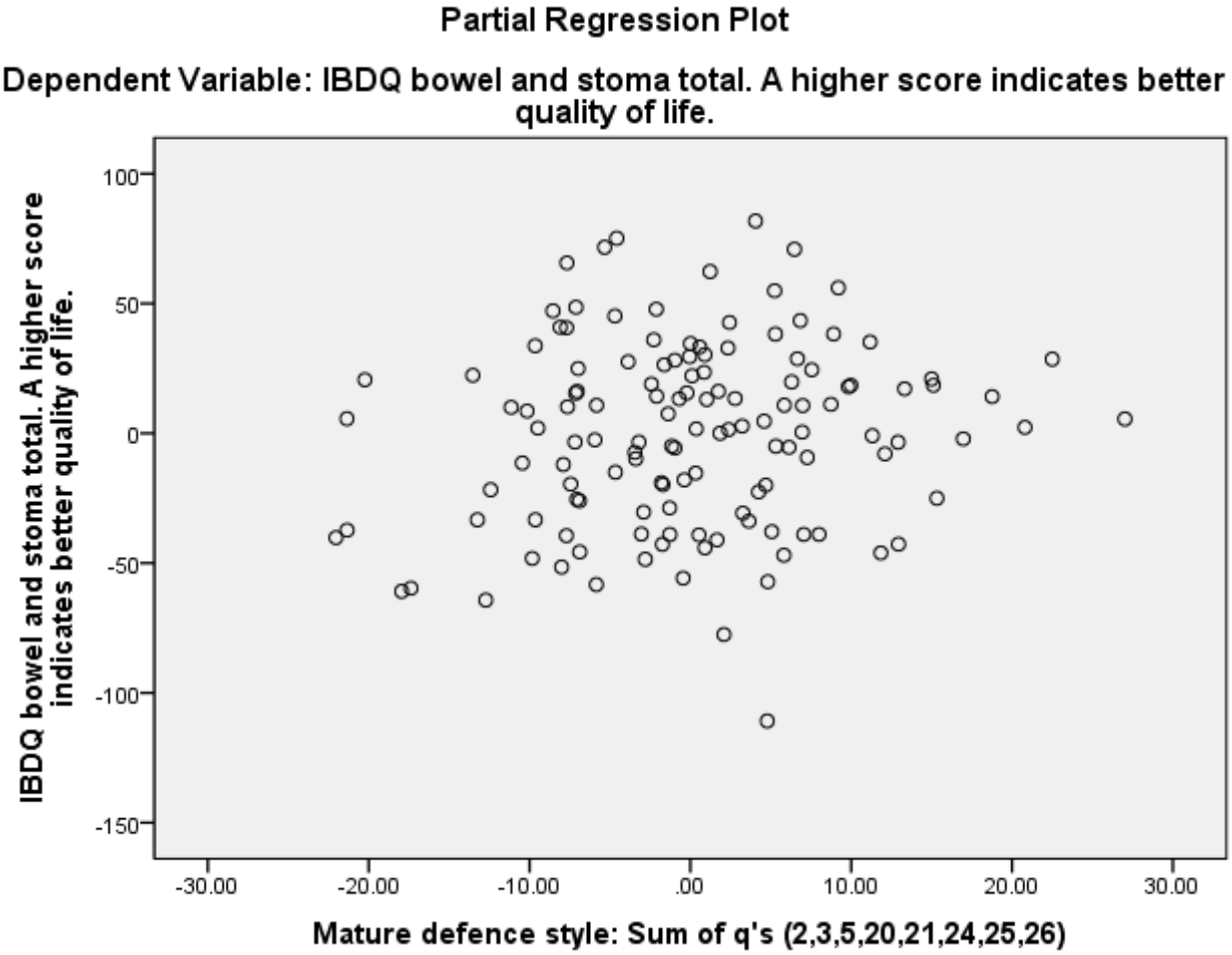
Illness perceptions



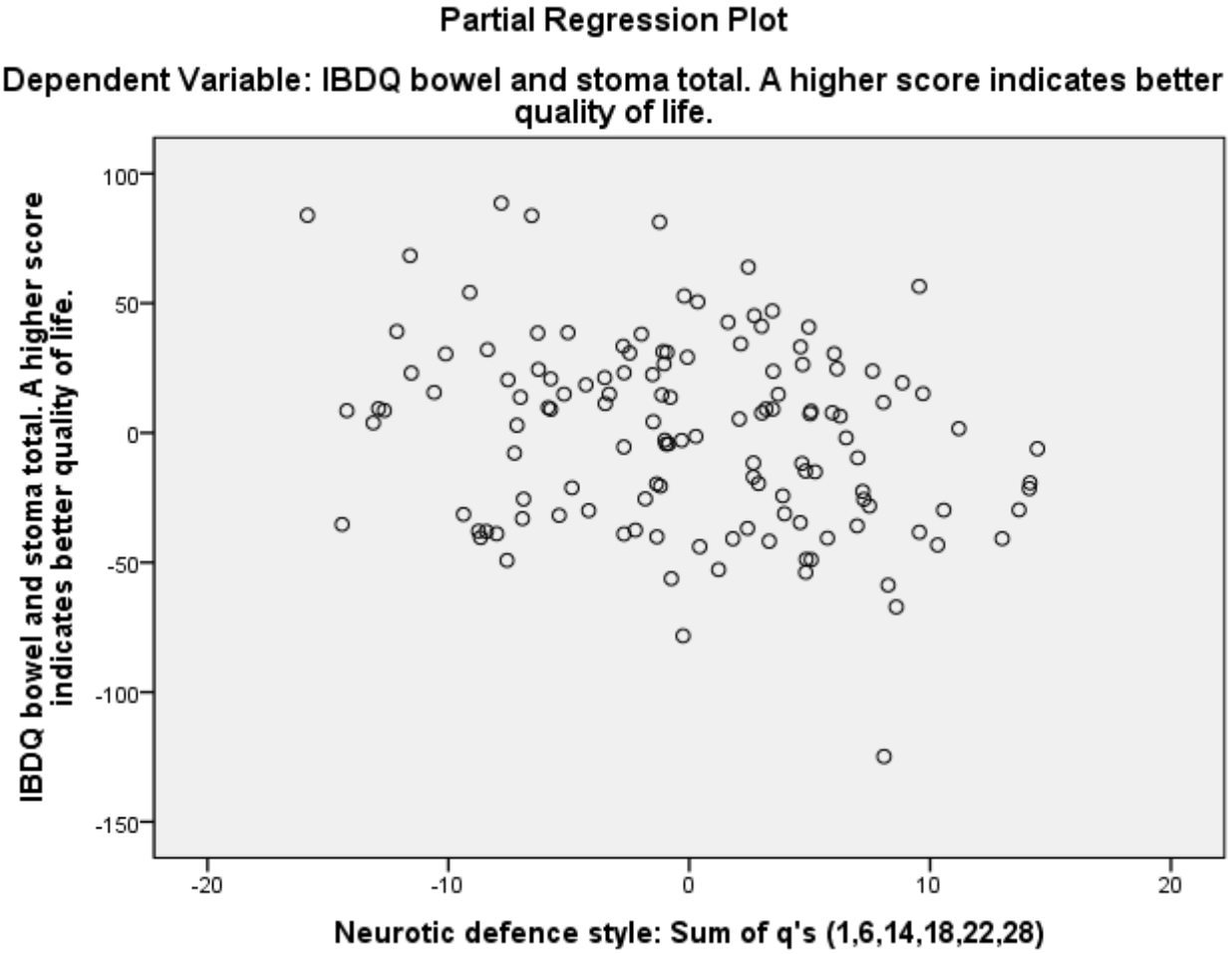
Alexithymia



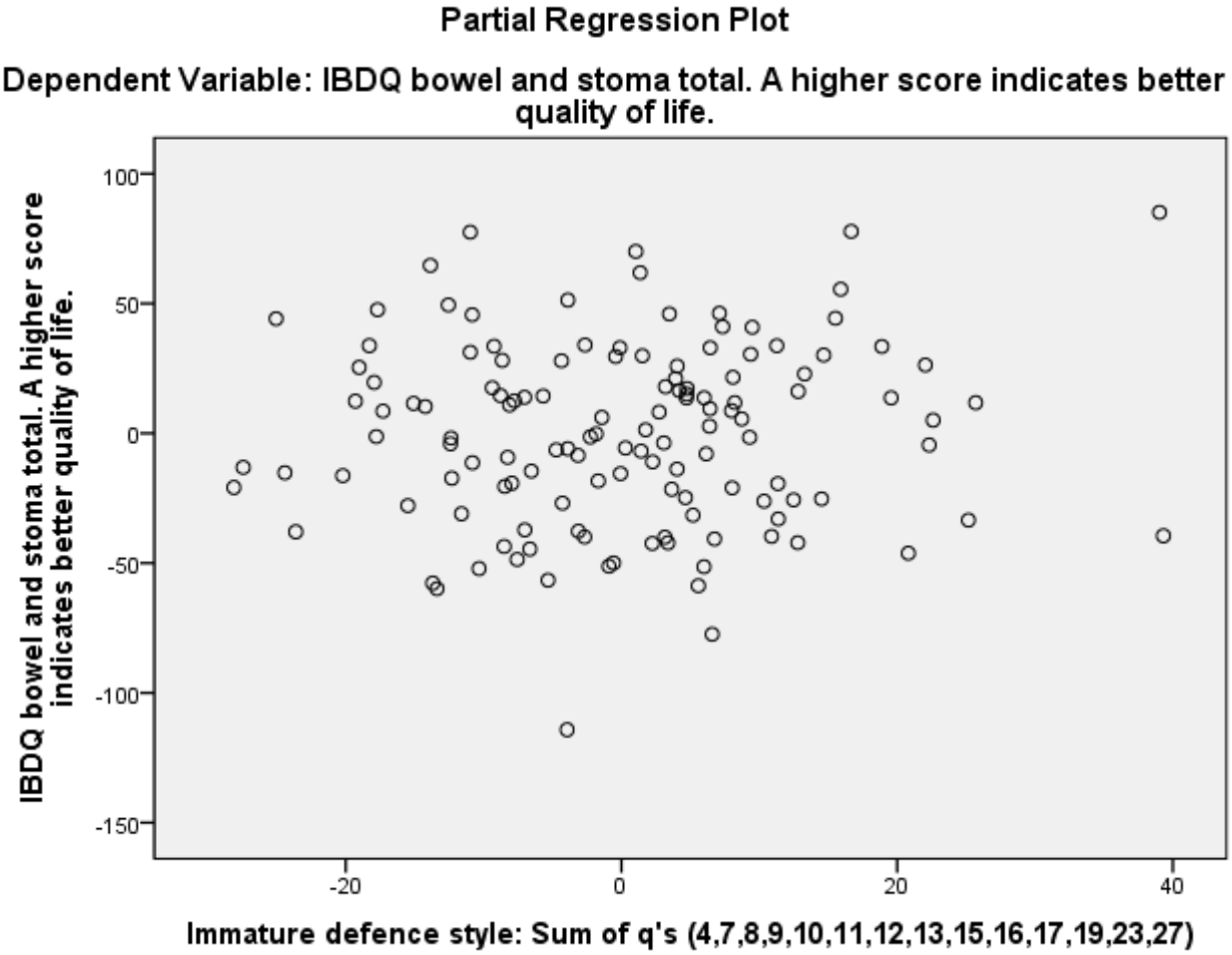
Mature defence styles



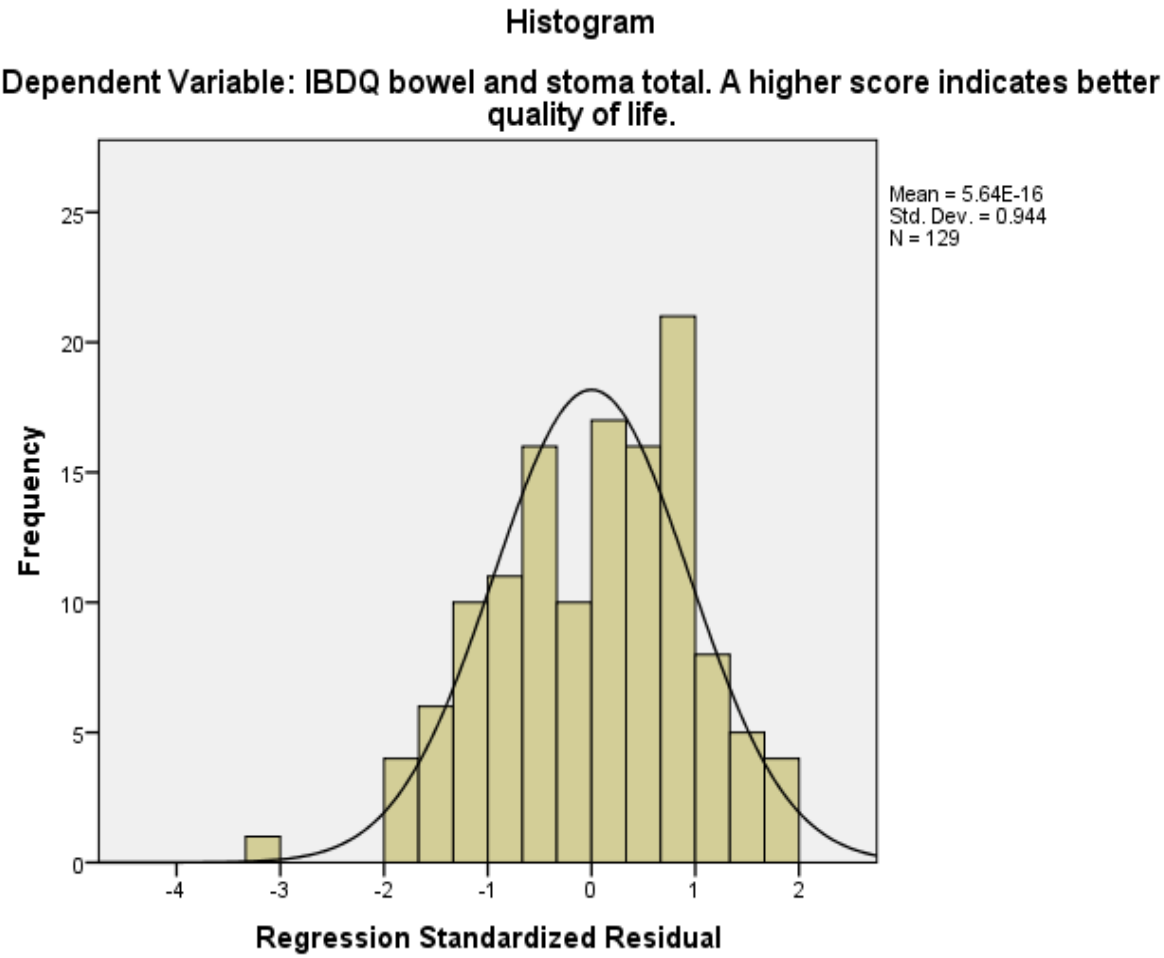
Neurotic defence style



Immature defence style



The residuals of the regression are normally distributed. Normal distribution is demonstrated by the histogram below.



Multicollinearity was checked by looking at VIF in the coefficients table following multiple regression. It is suggested that a VIF between 5 and 10, demonstrates correlation which could be a problem in using multiple regression. The predictors in the table did not go above 2.

Variables	VIF
Age	2.09
Crohnsvscolitis	1.51
Unclearvscolitis	1.15
Bothvscolitis	1.16
Gender	1.17
Diagnosis age –age	1.80
Other medical conditions	1.16
Difficulty identifying feelings	2.67
Difficulty describing feelings	2.79
Externally orientated thinking	1.45
Mature defence style	1.78
Neurotic defence style	1.69
Immature defence style	1.63
Illness perceptions	1.48

Reflective appendix

I kept a reflective diary throughout the process of completing the research project. This was useful, as it provided an opportunity to reflect on the learning experiences throughout the course of the research. For these experiences, I have organised my reflections using Gibbs (1988) reflective cycle.

Description: I found that both my initial large scale research project (LSRP) and my systematic literature review were not viable research options, and therefore had to be changed. My LSRP was changed after it became clear that I would not be able to get the participants to complete the study. The systematic literature review was changed prior to the write up, after I found that another researcher had published their proposal for the same systematic literature review, with the intention of publishing the full review the following month. Each of these changes led to me joining a new research team and developing a new project.

Feelings and evaluation: Although at the time, I was frustrated and disappointed that I had worked hard on projects that would not be pursued until the end; I was pleased and relieved that I had recognised the problems with the projects before they caused me major issues later on.

Analysis: My experiences of completing the large scale research project and the systematic literature review taught me about the reality of conducting research. My expectations were that my initial research project ideas would remain the same, from conception, to design to completion. However, I quickly learned that the reality of research is that it can collapse and not progress any further for reasons outside the researcher's control.

Reflecting on these experiences, it has taught me the importance of being flexible with project ideas and being honest as early as possible with the wider team and myself, about the likelihood of it being completed.

Conclusion: I have realised that there is not much that can be done to avoid these situations, and research is largely about accepting that these difficult situations might occur. However, in the future I will be more aware of the resources that I have available to me in assisting with this process.

Reflecting on this, I feel a big factor that can assist in navigating such difficult situations when they do occur is having an experienced and supportive team. I was very fortunate to work with two passionate and motivated teams who offered honest and useful advice about each of the projects whilst also encouraging me to take the lead from design to completion. From these experiences, I reflected about the importance of recognising the skills, knowledge and expertise that each team member brings to a project. I also learned about the importance of listening to this knowledge in making difficult decisions, such as whether to change a project.

I also reflected that it is important to trust my own skills. I feel that due to my interest in each of the completed projects, I was very motivated to research the topics, collect data and analyse the outcomes, with the hope of sharing this information with each of the populations.

As well as this, throughout the completion of the research, I reflected that I have further developed my organisational skills and time management skills, by managing university assignments, research projects, and placements; to

maintain a healthy work-life balance which I feel is important to learn and maintain in my future career.

Action plan: For my future research projects, it will be important for me to be aware of the possibility that a research project will collapse before it is completed, and to consider alternative approaches early on in the design process.

In future work, it will also be important for me to trust my team and also myself in being able to re-design and complete a new project. Although, it is frustrating and disheartening when effort has been put in to a project that does not make it to completion, my experience from this project has taught me that it is the reality of robust research.

I feel that I have learned a lot from the development and completion of these research projects, and although it has not always been a straight forward process, I feel that these experiences have taught me a lot about research and about myself. From these experiences, I feel I have progressed further in to a more adequate research- practitioner.